



House of Lords  
House of Commons

Joint Committee on the Draft  
Mental Incapacity Bill

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# Draft Mental Incapacity Bill

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Session 2002-03

*Volume I*

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9023

HL Paper 189-I  
HC 1083-I



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House of Commons

Joint Committee on the Draft  
Mental Incapacity Bill

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Session 2002-03

*Volume I*

*Report together with formal minutes*

*Ordered by The House of Commons  
to be printed 17 November 2003*

HL Paper 189-I  
HC 1083-I

Published on 28 November 2003  
by authority of the House of Lords and  
the House of Commons London: The Stationery Office Limited  
£16.50

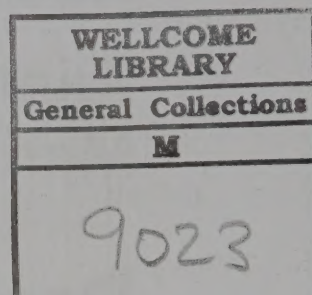


## The Joint Committee on the Draft Mental Incapacity Bill

The Joint Committee on the Draft Mental Incapacity Bill was appointed by the House of Commons and the House of Lords on Friday 11 July 2003 to examine the Draft Mental Incapacity Bill and report to both Houses no later than four months after the presentation of the draft Bill

### Current membership

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### Powers

The committee has the power to require the submission of written evidence and documents, to examine witnesses, to meet away from Westminster, to meet at any time, (except when Parliament is prorogues or dissolved), to appoint specialist advisers, and to make reports to the two Houses.

### Publication

The Report and evidence of the Joint Committee are published by The Stationery Office by Order of the two Houses. All publications of the Joint Committee (including press notices) are on the Internet at [www.parliament.uk/parliamentary\\_committees/jcmib.cfm](http://www.parliament.uk/parliamentary_committees/jcmib.cfm)

### Committee staff

The staff of the Committee were drawn from both Houses and comprised Gordon Baker and Sian Jones (Clerks), Francene Graham (Committee Assistant), and Melanie Moore (Committee Secretary). The Committee was supported by the Scrutiny Unit in the House of Commons Committee Office.

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## Summary

The draft Mental Incapacity Bill is the product of extensive consultation stretching back to 1989. We have been expected to scrutinise and report on it in little more than two months working time: an over-optimistic timescale which calls into question the process for setting deadlines for pre-legislative scrutiny. However we have considered over 1200 written submissions, heard evidence from 61 witnesses and have produced as thorough an analysis as possible in the time available.

On the whole, we endorse the principles and general direction of the draft Bill. The majority of evidence we received was broadly supportive of the Bill. We believe that there is a clear need for the bill and our report, whilst critical, should be read accordingly.

The difficulty of trying to create satisfactory legislation in this complex and sensitive area should not be underestimated. The draft Bill has provoked strong feelings, both positive and negative. We sympathise with some of the anxieties expressed, though we believe that many of them are misplaced.

Nevertheless, considering the long gestation period it has had, the draft Bill still has shortcomings. We believe those shortcomings can and should be rectified. Although a great deal of work remains to be done to get the Bill right, and strong feelings about it will undoubtedly remain, we hope it will soon be brought before Parliament. Those it is intended to help have waited long enough for the benefits it should bring them.

We endorse the draft Bill's widely-supported aim of replacing common law uncertainties by a comprehensive statutory framework to define mental capacity, help those lacking it to make their own decisions where they can and enable sound decisions to be made for them when they can not.

We believe that the Bill should follow the model of the comparable Scottish law by setting out the guiding principles at the start. While this may not be necessary for lawyers, it will undoubtedly be helpful for the many lay people likely to be affected by it and will set clear guidelines around which good practice can be developed.

The draft Bill rests on a combination of the well-established common law principle of best interests and the presumption of capacity. We think this approach is sound. The Bill should be seen as enabling rather than restrictive, although it has to strike a delicate balance between respect for individual autonomy and the need to protect the vulnerable.

We acknowledge the difficulties inherent in trying to create a satisfactory legislative framework for mental capacity of varying degrees, from temporary to permanent and including fluctuating capacity, and for decisions ranging from the everyday to the life changing.

The draft Bill's yardstick of functional capacity – assessing capacity in relation to the required decision at the time when it is needed – seems right. The concept of best interests is the draft Bill's other cornerstone. This is well-enough understood by lawyers, but perhaps open to misinterpretation by others. Decision-makers must be clear about what is expected.

The draft Bill introduces the new concept of General Authority. This is intended to replace the common law defence of necessity with positive permission-giving arrangements for



taking everyday and emergency decisions. The concept has been widely misunderstood and the term “authority” itself seems to have negative connotations for some who fear it amounts to licensed paternalism. Consideration should be given to a more appropriate term.

Proposals in the draft Bill would extend the present Enduring Powers of Attorney to a new Lasting Power of Attorney, which will include decisions on welfare and healthcare as well as financial management. We received disturbing evidence indicating serious abuse of financial powers under the present Enduring Powers of Attorney which the Bill must strive to curb. Stricter safeguards will be needed and those who act under these powers will need clear guidance on what is involved and be required to keep adequate records of financial transactions.

We welcome the draft Bill’s proposal to introduce a new Court of Protection: a more accessible single jurisdiction with powers and authority akin to those of the High Court. But we are concerned over the apparent limitations on availability of legal aid. Deputies appointed by the Court to take decisions on behalf of those lacking capacity will need clear standards of conduct and limitations on their autonomy. They should not take decisions on life-sustaining treatment.

One of the most controversial aspects of the draft Bill would enable those with capacity to make advance decisions to refuse medical treatment should they become incapable. This provoked strong moral objections and wide-spread concern that it could lead to euthanasia by the back door. Although we are satisfied that nothing in the draft Bill would permit euthanasia, it may be advantageous for the Bill to incorporate additional assurances on this point.

In our view, it is right that those who have capacity should be able to state in advance what medical treatment they would not want to have in case they become incapable of taking decisions. The consequences of those decisions need to be properly explained to them. The decisions themselves should be made in writing and independently witnessed in almost all cases, and regularly reviewed. Doctors must satisfy themselves that advance decisions are valid in relation to the treatment concerned. Guidance is needed on standards of care and the particular problems posed by artificial nutrition and hydration.

Any new mental health legislation should take careful account of the criteria for judging capacity established by this Bill. Some grey areas between the draft Bill and the present Mental Health Act (notably the so-called “Bournewood Gap”)<sup>1</sup> need to be addressed.

The Codes of Practice will be absolutely critical for the success of the Bill. It must be clear, comprehensive and workable. It must also be accompanied by a publicity campaign to explain what the Bill is all about, and by readily-understandable guidelines for informal carers, families and others helping those lacking capacity to make decisions, as well as those with learning difficulties.

A great deal remains to be done on the Codes of Practice. Parliament must see the Code in draft when the Bill is introduced, but the work still needed on this should not hold up the introduction of the Bill.

<sup>1</sup> See Chapter 12, page 60



We also looked at what the draft Bill does not cover. It needs to say much more than it does about protection against abuse and exploitation of those lacking capacity. The new Office of the Public Guardian and other statutory bodies should have powers to investigate and intervene to protect vulnerable people from abuse.

Some of our respondents were strongly opposed to allowing medical research on those lacking the capacity to give consent. After careful consideration, we concluded that the Bill should allow it in limited circumstances under strict controls administered through medical ethics committees.

We believe the Bill should acknowledge the valuable role that independent advocacy services can play in helping those lacking capacity to assert their rights, provide additional safeguards against abuse and exploitation and help to resolve disputes. The status of independent advocates needs to be officially recognised and their availability and standards should be improved.

It is most regrettable that the Department was only able to provide inadequate estimates of the likely resource impact of the Bill very late in our Inquiry. Both Houses will need to take a very thorough look at the resource implications when the Bill is presented to them.

The draft Bill should also cover access to information for those lacking capacity and their helpers. The rights to privacy of those lacking capacity should be respected and protected. Yet those acting for them do need access to information if they are to carry out their responsibilities properly and provide effective assistance.

We are also surprised that jurisdictional issues arising from the differences between the draft Bill and the counterpart Scottish legislation have not been addressed. We welcome the Department's assurance that they will be when the Bill itself is presented to Parliament.

Altogether we have made nearly 100 recommendations about the draft Bill.<sup>2</sup> We expect the Government to give them the utmost consideration as a matter of priority.

One of those recommendations is that the Bill's title should be changed to the Mental Capacity Bill. We think this reflects more accurately what the Bill is about and removes some of the more pejorative undertones regrettably associated with incapacity. We hope that change will symbolise the changes in public attitudes and understanding which are long overdue and which this Bill should help to bring about.

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<sup>2</sup> See Chapter 2, page 11

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# 1 Chapter 1 Background to the Draft Bill:

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1. The Draft Mental Incapacity Bill<sup>3</sup> and accompanying Commentary and Explanatory Notes<sup>4</sup> were presented to Parliament on 27 June 2003 by Lord Filkin, the Parliamentary Under-Secretary of State for the newly-created Department for Constitutional Affairs.

## **Consultation**

2. The draft Bill is the result of a very lengthy and detailed process of consultation. As long ago as 1989, the then Lord Chancellor, Lord MacKay of Clashfern, invited the Law Commission of England and Wales to carry out a comprehensive investigation of all areas of the law affecting decisions on the personal, financial and medical affairs of those who lack capacity. This was in response to concerns raised by professional bodies and voluntary organisations dealing with mental disability

3. Following five years of consultation and deliberation, the Law Commission produced its final report and recommendations for Law Reform in March 1995.<sup>5</sup> The Commission recommended that “there should be a single comprehensive piece of legislation to make new provision for people who lack mental capacity”.<sup>6</sup>

4. The Commission’s recommendations for legislation included a new statutory definition of what it meant to be “without capacity” to make a particular decision. This was coupled with statutory criteria defining the “best interests” of the person concerned as the basis on which decisions might be made by others on behalf of a person lacking capacity.

5. The report also proposed the concept of “General Authority” to clarify where action might lawfully be taken on behalf of a person lacking capacity without needing formal procedures or intervention by the court. This would provide legal authorisation for anyone to “do anything for the personal welfare or healthcare of a person who is, or is reasonably believed to be, without capacity in relation to the matter in question if it is in all the circumstances reasonable for it to be done by the person who does it, and it is in the best interests of that person”.<sup>7</sup>

6. The Commission also recommended that persons aged 18 or over who had the necessary capacity to make decisions could express advance refusals of medical, surgical, dental or other procedure which might be available to them in future when they lacked the capacity to express that decision.<sup>8</sup> Other recommendations of the Law Commission included:

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<sup>3</sup> Cm 5859-1

<sup>4</sup> Cm.5859-II

<sup>5</sup> Law Commission Report 231, Mental Incapacity, HMSO 28 February 1995

<sup>6</sup> Ibid Summary paragraph 1.2

<sup>7</sup> Ibid Summary 1.6

<sup>8</sup> Ibid 1.14

- Provisions for the supervision of particular forms of invasive or irreversible medical treatment and permitting, in certain circumstances and under strict safeguards, non-therapeutic medical research, involving persons lacking capacity;<sup>9</sup>
- A new form of Power of Attorney to be called a “Continuing Power of Attorney” to provide for designated persons (known as “donees”) to be authorised to make and implement decisions about personal welfare, health care and financial affairs in the best interests of those lacking capacity;<sup>10</sup>
- An integrated statutory jurisdiction for making personal welfare, health care and financial decisions on behalf of those lacking capacity and for resolving disputes through a new Court of Protection;<sup>11</sup>
- Public Law Protection for vulnerable people at risk by giving social services departments a duty to investigate possible harm or serious exploitation of vulnerable persons and to intervene where necessary.<sup>12</sup>

7. In response to the Law Commission Report, the (then) Lord Chancellor’s Department published a Green Paper “*Who Decides*” in December 1997<sup>13</sup> and, after a further consultation, a policy statement entitled ‘Making Decisions’ in October 1999.<sup>14</sup> This set out<sup>15</sup> the Government’s commitment to bring forward new legislation “when Parliamentary time allows” to include:

- A presumption against lack of capacity;
- A functional approach to determining whether or not a person has capacity to make a particular decision;
- A new statutory definition of incapacity;
- A commitment that all practical steps must be taken to enable a person without capacity to communicate their decisions;
- Statutory guidance on how the best interests of person who lacks capacity should be determined;
- A General Authority to react reasonably for “day-to-day decision making on behalf of those without capacity”, but subject to certain restrictions;
- New provisions on continuing Powers of Attorney enabling the delegation of decision making powers on finance, health care and personal welfare by persons over the age of 18;

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<sup>9</sup> Ibid 1.21-23

<sup>10</sup> Ibid 1.27

<sup>11</sup> Ibid 1.34-1.41

<sup>12</sup> Ibid 1.45

<sup>13</sup> CM 3803

<sup>14</sup> CM 4465

<sup>15</sup> Ibid, Chapters 1-3

- A new single Court of Protection to deal with all the areas of decision making for adults without capacity;
- A commitment to ensure that appropriate arrangements should be put in place to provide a practical and effective system to monitor health care, welfare and financial management of those lacking capacity.

8. Following the publication of the Green Paper, the (then) Lord Chancellor's Department established the **Mental Incapacity Consultative Forum**. This was designed to work with stakeholder organisations, to develop solutions to problems which exist under the current law and to explore proposals for new legislation. The Department also produced a series of six booklets giving guidance on the existing law respectively for legal practitioners, social care professionals, health care professionals, family and friends, people wishing to prepare for possible future incapacity and those with learning difficulties.<sup>16</sup> Meetings and consultation seminars with those representative groups, organised by the Department, to discuss the scope for law reform eventually led to publication of the draft Bill.

### Scotland

9. In parallel with the work of the Law Commission of England and Wales, the Scottish Law Commission carried out a similar consultative exercise in the early 1990's which culminated in its own final report published in 1995. Following further consultation and a position paper "*Making the Right Moves*" published in 1999<sup>17</sup>, the **Adults with Incapacity (Scotland) Act 2000**<sup>18</sup> became one of the first statutes to be enacted by the Scottish Parliament. The Scottish Act has been implemented in stages and the Scottish Executive has commissioned surveys to find out how the Act is working in practice and what impact it is having on those without capacity and their carers.

10. Many of the provisions of the Adults with Incapacity (Scotland) Act 2000 mirror those proposed for England and Wales in the Draft Mental Incapacity Bill. But differences between the respective jurisdictions and the different public bodies responsible for legislation are reflected in some important differences in approach. The main differences are highlighted where appropriate in the relevant sections of this Report.

## 2 Chapter 2: Conduct of the Inquiry

11. Following an initial motion in the House of Lords on 12 June, the Joint Committee was set up following resolutions of both Houses on 9 and 11 July 2003 respectively<sup>19</sup> with a remit to report on the draft Bill by the end of November 2003. A list of Committee Members is given on the inside cover of the Report.

<sup>16</sup> <http://www.lcd.gov.uk/family/mi/index.htm>

<sup>17</sup> SE/1999/24, ISBN 0 10 888002 8

<sup>18</sup> 2000 asp 4

<sup>19</sup> HC, Vol. 408, Cols 1481-2, 10 July, HL, Vol. 651, Col 570, 574, 11 July



12. Our first meeting was held on 15 July 2003, when Lord Carter was elected Chairman by acclamation. Because of the impending Parliamentary Summer Recess, it was not possible for us to meet again until 9 September 2003. At that meeting, Professor Anthony Holland and Ms Penny Letts were appointed as Specialist Advisers to the Joint Committee.

13. We issued a combined Call for Evidence and Press Notice on 17 July 2003.<sup>20</sup> This noted that we expected to concentrate our Inquiry on the following themes in relation to the structure and content of the draft Bill:

- Was the consultation process preceding the publication of the draft Bill adequate and effective?
- Are the objectives of the draft Bill clear and appropriate?
- Does the draft Bill meet those objectives adequately?
- Are the proposals in the draft Bill workable and sufficient?
- Might lessons be learned from similar legislation already implemented in Scotland or elsewhere?
- Are there relevant issues not covered by the draft Bill which it should have addressed?
- In what other ways might the draft Bill be improved?

14. With so little time available to complete the Inquiry, because of the Summer Recess, we decided that the deadline in our Call for Evidence for submission of memoranda should be set at 1 September 2003. Understandably, this provoked numerous complaints from those who said they would have great difficulty in meeting our deadline. We regret the inconvenience caused, but it was unavoidable: we wanted to allow as much time as possible for written submissions to be considered before we started taking oral evidence, but equally realised that we would have to start taking oral evidence, but equally realised that we would have to start taking oral evidence as early as possible in September so as to give as many witnesses as possible the opportunity of addressing us.

15. In practice, we decided to accept and consider written memoranda long after the 1 September deadline had expired. Altogether we received over 1200 separate written submissions, all of which were circulated to Committee Members and given due consideration.

16. Between 10 September and 22 October we held nine oral evidence sessions at which evidence was given by a total of 61 witnesses, culminating in evidence from the Parliamentary Under-Secretary of State for Constitutional Affairs, Lord Filkin, and the Minister of State at the Department of Health, Ms Rosie Winterton.

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<sup>20</sup> See Annex A

17. Details of the witnesses giving oral evidence are listed. Transcripts of the oral evidence given are published in Volume 2 of this Report. We decided it would not be possible to publish all the written memoranda received, but a selection is printed in Volume 2 of this Report together with a list of all those who submitted written memoranda.

18. We are very grateful to all those who submitted written memoranda and especially to those who spared time, often at very short notice, to give us the benefit of their knowledge and experience in oral evidence.

19. It has been a daunting task to assimilate all this evidence in such a brief time, especially given the complexity and sensitivity of the draft Bill and the strong opinions expressed about it.

20. We have been greatly assisted in this task by our two Specialist Advisers, whose expertise, sound advice and willingness to work under great pressure have been outstanding. We must also pay tribute to the hard work and skill of the Committee staff, who are listed on the inside cover of this Report.

21. With hindsight, the deadline set for the Committee was clearly unrealistic. The delay in publication of the draft Bill, compounded by the delay in setting up the Committee, meant that we could do little work as a Committee until mid-September against a deadline of the end of November. We have worked hard and done our best but the importance of this draft Bill, and the complexity and sensitivity of the issues involved, deserved much more time and careful consideration than we have been able to give.

22. **We recommend that consideration be given to a new procedure for setting deadlines for Joint Committees carrying out pre-legislative scrutiny to enable them to give full and proper consideration to all the issues involved and to allow those wishing to offer evidence to the Committee a fair and adequate opportunity to do so.**

23. We understand that the timescale was partly driven by an initial perception that the Government intended to bring forward legislation based on the draft Bill early in the next Parliamentary session. **We appreciate that this Inquiry has given the Government much more food for thought about the Bill. We also recognise that the difficulties and implications raised later in this Report will need to be dealt with in consequential amendments. Nevertheless, we would be extremely disappointed if the Government felt unable to continue to give the Bill due priority. Those whom it is intended to help have waited long enough and deserve to have the benefits which the new legislation can bring in the very near future.**

### 3 Chapter 3: Is the Bill necessary?

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24. The evidence we have received has highlighted the widespread support for the introduction of a Bill dealing with issues related to mental incapacity. Most of our witnesses acknowledged the benefit of having a bill which would provide a comprehensive statutory framework for assisting those lacking capacity to make decisions for themselves

wherever possible and would allow for decisions to be taken properly on their behalf and in their best interests when they lack that capacity. The many criticisms we have received have focused on the content of the draft Bill rather than its objectives.

25. We recognise that it is no easy task to design a legal framework enabling satisfactory decisions to be made in situations ranging from temporary incapacity, fluctuating capacity to permanent incapacity and covering everything from everyday necessities to major life-changing actions.

26. We accept that particular difficulties may be involved in trying to establish the wishes of those whose learning disability or lack of communications skills may conceal their ability to make decisions.

27. We also appreciate that all decisions, however minor and routine, affect people in their daily lives and that small decisions often have a disproportionate effect on the morale and quality of life of those who are disadvantaged or vulnerable.

28. Against this background, we have reviewed evidence as indicated in this Report which demonstrates:

- the inadequacies of the present common law;
- the need to promote awareness and good practice in dealing with those lacking capacity;
- the Government's duty to fulfil human rights obligations towards those lacking capacity;
- the Government's commitment to promote non-discrimination; and
- the need to achieve a better balance between autonomy and protection for those who are unable to make decisions.

29. We acknowledge the limitations of prescriptive legislation in addressing these problems. We believe that this Bill must be enabling as well as protective. But it is not just about making legal changes. It is about the need to change deep-seated attitudes and ways of thinking. In this context, perception is often more important than reality and it is vital to find language which will set the right tone and invoke the desired response whilst meeting legal requirements.

30. We concur with the widely-held view that a new Bill is needed to provide a comprehensive statutory framework for assisting those lacking capacity to make decisions for themselves wherever possible and for proper decisions to be made by others on their behalf where that is not possible. Even so, legislation can only go so far. It must be accompanied by changes in attitude which recognise the rights of those lacking capacity and the need to instil respect and good practice in dealing with them. The Bill must aim to preserve a satisfactory balance between enablement and protection.



## 4 Chapter 4: Principles of the Bill

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31. The Commentary and Explanatory Notes issued by the Department for Constitutional Affairs to accompany the draft Bill<sup>21</sup> described the Key Principles of the Bill as a combination of: "... a single definition of capacity that requires capacity to be assessed according to each decision that needs to be taken" and enshrining in statute the concept of "acting in the best interests of a person who lacks capacity...as the overriding principle that must guide all decisions made on behalf of someone lacking capacity"

32. This document also says that individuals will not be labelled "incapable" but only "regarded as lacking capacity for certain decisions at the time that that decision (sic) needed to be taken". It points out that "in many cases individuals are quite capable of making some decisions", although they may find others more difficult and goes on to say: "The approach to establishing whether someone has capacity used in the Bill is underpinned by the belief that whenever possible individuals should continue to make as many of their own decisions as possible. The starting point is always that the person has capacity and the Bill states that 'all practicable steps' must be taken to help the person make the decision before they can be regarded as lacking the capacity to make that decision".<sup>22</sup>

33. It is also pointed out in the Commentary and Explanatory Notes that the Bill includes a checklist of factors that decision makers must take into account when considering what is in the best interests of the person concerned so as to "provide a common standard around which all interested parties should discuss and agree how to make a decision for the person who lacks capacity."<sup>23</sup>

34. In correspondence with the Chairman of the Joint Committee, Parliamentary Under-Secretary of State for the Department for Constitutional Affairs, Lord Filkin, has set out what the Department regards as the objectives of the Bill as being to: "maximise the capacity of those who lack or who may lack capacity to take certain decisions for themselves; protect vulnerable adults with mental incapacity issues from abuse and neglect; and, provide clarity to families, informal carers and professionals as to when they may act or take decisions on behalf of those incapable of making such decisions themselves."

35. In oral evidence to the Committee on 22 October, Lord Filkin described the Principles of the draft Legislation as follows:

"The best interest is one of the principles – probably it is a fundamental principle. It is really saying that where people are making decisions in a situation where there is not capacity and they are not at liberty to act at large; they can only act in terms of the best interest. Secondly, there are a number of other principles in our Bill: the presumption of capacity, the functional test of capacity...in other words, making a judgment about capacity at the specific point in time when you need to rather than

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<sup>21</sup> CM 5859-II, page 7

<sup>22</sup> Ibid

<sup>23</sup> Ibid

speaking once and for all. There is a requirement to take all practical steps to help people make decisions, in other words, not just making it a black and white issue. Also, when it is clear that a person does not have capacity, still striving to take their wishes into account.”<sup>24</sup>

36. These principles are incorporated in Part 1 of the Bill which defines lack of capacity (Clause 1), inability to make decisions (Clause 2), the presumption against lack of capacity (Clause 3) and best interests (Clause 4). The latter includes the checklist of factors to be considered by anyone taking decisions in the best interests of someone lacking capacity.

37. Unlike its Scottish counterpart, the Adults with Incapacity (Scotland) Act 2000<sup>25</sup>, however, the draft Bill does not have a specific statement of the fundamental principles on which it is based. Section One of the Scottish Act sets out five general principles which govern all “interventions” taken in the affairs of an adult under, or in pursuance of, the Act. These are:

- There shall be no intervention ... unless that intervention will *benefit* the adult and that such benefit cannot reasonably be achieved without the intervention.
- the intervention must be the least restrictive option in relation to the adult’s freedom.
- In deciding on any intervention, account must be taken of the adult’s past and present wishes and feelings so far as they can be ascertained by any means of communication, whether human or by mechanical aid.
- Account must be taken of the views of relevant others (including the nearest relative and primary carer) where it is reasonable and practicable to do so.
- People holding certain powers under the Act (e.g., attorneys and guardians) must encourage the adult to use existing skills, and to develop new skills, concerning his/her property, financial affairs or personal welfare.

38. Section One of the Scottish Act also contains the “fundamental definitions” which apply in relation to the Act, including the definitions of “adult” and “incapable”, thus defining the people to whom the Act applies. The presumption of capacity is established under Common Law and is not re-stated in the Act. Thus the Scottish Act is designed to run in conjunction with the Common Law, whereas the draft Bill is designed to codify existing Common Law practice in statute.

39. We examine these differences of approach in more detail in the relevant sections of the Report. However, we were struck by the absence of a specific statement of principles on the face of the Bill as an initial point of reference, as has been done in the Scottish Act. Although the principles of the draft Bill may be discernible to lawyers from the opening

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<sup>24</sup> Q723 (Lord Filkin)

<sup>25</sup> 2000 asp 4



clauses of the draft Bill, they may not be so obvious to the majority of non-legal persons who will have to deal with the Bill in practice.

40. Several witnesses told us they would see advantage in having such a statement of principles on the face of the Bill.<sup>26</sup> In particular, our attention was drawn to the principles set out in section 1 of the Children Act 1989 and, as an example of more recent legislation, to the Adoption and Children Act 2002, which set out in section 1 specific 'Considerations applying to the exercise of powers' under that Act.<sup>27</sup>

41. When we asked Lord Filkin about this in oral evidence he said

"We are certainly open to reflection as to whether it would give people more comfort to put some of those principles altogether in one section. We are not saying that we will do that, but we need to think about why we should not have a section making it very clear rather than requiring the effort of going through the whole Bill to find the principles at various points in it".<sup>28</sup>

42. In an enclosure to a subsequent letter to the Chairman, Lord Filkin added:

"We agree that the perception of the Mental Incapacity Bill is important and we have heard that the Scottish style of a clear statement of principles in the Bill has been well received. Therefore, we are content to investigate whether it would be possible to amend the draft Mental Incapacity Bill to similar effect and give more emphasis to the principles given above. Of course, we will need to take advice from Parliamentary Counsel as to the possibility of achieving this."<sup>29</sup>

43. We welcome the Department's commitment to give further consideration to the possibility of incorporating a statement of principles on the face of the Bill. We believe that such a statement inserted as an initial point of reference could give valuable guidance to the Courts, as well as helping non-lawyers to weigh up difficult decisions. Evidence given to us indicates this would be welcome to a wide range of those who have to deal with the problems of substitute decision-making in practice. We also believe that such a statement would be valuable in helping to frame the Codes of Practice based on the Bill.

44. We further recommend that the statement of principles should include the following:

- Every adult has the right to make his/her own decisions and must be assumed to have capacity to do so unless it is proved otherwise

<sup>26</sup> Q164 (Mr Kramer), Q177(Mr Broach), Ev 85 MIB 1188, Q273 (Dr Wilks), Q284 (Professor Murphy), Q446 (Mr Dixon), Q548, Q555, Q556 (Mr Clements)

<sup>27</sup> Baroness Barker, Private session 23October 2003

<sup>28</sup> Q723 (Lord Filkin)

<sup>29</sup> Ev 284 MIB 1221 Annex 3

- Everyone should be encouraged and enabled to make his/her own decisions, or to participate as fully as possible in decision-making, by being given the help and support s/he needs to make and express a choice
- Individuals must retain the right to make what might be seen as eccentric or unwise decisions
- Decisions made on behalf of people without capacity should be made in their best interests, giving priority to achieving what they themselves would have wanted
- Decisions made on behalf of someone else should be those which are least restrictive of their basic rights and freedoms”.

## 5 Chapter 5: Human Rights Considerations

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### Human Rights Act Compatibility

45. After examination of the draft Bill, the Joint Committee on Human Rights concluded:

“... its provisions engage a wide range of rights, including the right to respect for private life, the right to property, and the right to be free of degrading treatment. In our view, the safeguards built into the draft Bill are sufficient to ensure that there is no significant risk of the implementation of the Draft bill leading to an incompatibility with any of them.”<sup>30</sup>

46. Given that the draft Bill would clearly invoke rights under the Human Rights Act 1998, the Committee undertook its own scrutiny of the issues. Professor John Williams, Head of the Law Department of the University of Wales, Aberystwyth, stated in his evidence to the Committee:

“...the common law on decision making for incapacitated people has served us reasonably well and facilitated decision making for incapacitated people, it is doubtful whether it contains sufficient safeguards to ensure that it does not violate the European Convention on Human Rights ....”<sup>31</sup>

47. Accordingly, the current practice of relying on the courts to fill in the gaps in the law was clearly seen as inadequate and the clarity of a statutory footing was viewed as desirable.<sup>32</sup>

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<sup>30</sup> Scrutiny of Bills and draft Bills: Further Progress Report (HL Paper 149/HC 1005), para 4.7

<sup>31</sup> Ev 190 MIB 564 para 2

<sup>32</sup> See Re F (Adult: Court’s jurisdiction) [2000] 2 FLR 512



“The draft Bill is welcome and very timely. Incapacity is a growing area of concern for social work practitioners and most feel uncomfortable working under the existing system.”<sup>33</sup>

48. Despite the report from the Joint Committee on Human Rights, it became apparent to the Committee quite early on in our inquiry, that there remained significant disagreement as to the Human Rights implications of the draft Bill. Oral evidence from Values into Action, an organisation working with people with learning difficulties stated:

“As is currently drafted in my view this Bill legalises what is currently done by and large unlawfully in terms of decision-making being done on behalf of other people. At the moment because the law is so unsatisfactory many, many decisions are made for people with no legal basis. This Bill if it were to go ahead would legalise that position without ensuring those decisions are what people want and without ensuring that people's views are properly and thoroughly taken into account, it would actually worsen the situation of people with learning difficulties.”<sup>34</sup>

49. A number of submissions were received from witnesses expressing concern about the impact of the draft Bill on the rights enshrined in the articles of the European Convention on Human Rights, now incorporated into UK law by the 1998 Act. Those which the Committee received the most evidence on were articles 2 and 6.

### **Article 2(1) provides:**

“Everyone's right to life shall be protected by the law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which this penalty is provided by law”<sup>35</sup>

50. Article 2 therefore imposes a primary obligation on the State to refrain from taking life, other than in limited circumstances. It further imposes a secondary obligation to ensure that there are appropriate safeguards in place to protect life.

51. Evidence from ALERT, an organisation committed to “defending vulnerable people's right to live” submitted to the Committee the opinion of leading counsel, Richard Gordon QC, in which it was stated:

“Article 2.....imposes a positive obligation on the State to give life-sustaining treatment in circumstances where, according to responsible medical opinion, such treatment is in the best interests of the patient”<sup>36</sup>

52. It was submitted that the powers in the draft Bill, exercisable under Lasting Powers of Attorney and by the refusal of treatment by advance decisions, contravened, *inter alia*, the obligations of the State under article 2. However, a number of other witnesses submitted

<sup>33</sup> Ev 190 MIB 564, para 2

<sup>34</sup> Q653 (Dr Collins)

<sup>35</sup> Ev 433 MIB 933 para 45(a)

<sup>36</sup> para 45(a)

that although article 2 does impose positive duties on the State to uphold an individual's right to life, a public authority cannot be compelled to impose treatment against a person's express wishes.<sup>37</sup> Accordingly, an individual can refuse to have his right to life upheld and relieve the State from its obligation. Moreover, on a number of occasions, the courts have upheld the right of an individual with capacity to refuse life-sustaining treatment even if that decision is irrational.<sup>38</sup>

**53. We are of the opinion that under the proper interpretation of article 2, the State has a secondary obligation to protect life, but an individual can choose not to uphold that right. Accordingly, the mechanisms under the draft Bill, which permit the refusal of consent to the carrying out or continuation of treatment, in accordance with the wishes of the patient, do not contravene article 2 of the European Convention on Human Rights.**

**Article 6(1) provides:**

54. In the determination of his civil rights and obligations or of any criminal charge against him, everyone is entitled to a fair and public hearing within a reasonable time by an independent and impartial tribunal established by law.<sup>39</sup>

55. It was submitted to the Committee that, first, the right of access to the Court of Protection was 'inadequate to comply with the need for immediate access to a Court...' and secondly, that there were no obvious mechanisms for the Court to become involved.<sup>40</sup>

56. It has been held that the right of access to court is not absolute, but may be subject to limitations, since 'by its very nature [it] calls for regulation by the state, which may vary in time and place according to the needs and resources of the community and of individuals'.<sup>41</sup> The draft Bill does provide a right of access to the courts as it is possible to challenge decisions, and others can challenge on behalf of the incapable adult. Under clause 40 a number of individuals can apply to the Court of Protection without permission, including the incapacitated person him/herself, anyone acting on behalf of the person lacking capacity (such as a litigation friend), a donee of a lasting power of attorney and a court appointed deputy. In certain situations, the very nature of person's incapacity will mean that access to court by that individual will be more difficult than for a capable person. The aim of the draft Bill is to provide mechanisms for substitute decision making for incapable adults; by dispensing with the requirement to obtain permission in some cases, it attempts to increase access to the Court. Permission cannot be dispensed with in all cases as gatekeeping mechanisms need to be maintained. Moreover, Professor Michael Gunn of Nottingham Law School argues that to allow all decisions to be determined by the court could amount to a breach of the article 8 right to have private life protected.<sup>42</sup> The essential

<sup>37</sup> Q150 (Mr Foster), Q607 (Mr Clements)

<sup>38</sup> eg *Re T* [1992] 1 WLR 782; *Re B (adult: refusal of medical treatment)* [2002] 2 All ER 449

<sup>39</sup> Schedule 1, Human Rights Act 1998

<sup>40</sup> Ev 433 MIB 933, para 61

<sup>41</sup> *Golder v United Kingdom* (1975) 1 EHRR 524, quoted in *Human Rights Practice* (June 2000) Jessica Simor (ed)

<sup>42</sup> Ev 416 Ev 416 MIB 1192, para 7b

object of article 8 is the protection of the individual against arbitrary interference by public authorities.

**57. Although we have made recommendations that access to the Court of Protection should be further enhanced for persons lacking capacity<sup>43</sup> we are of the opinion that there are sufficient mechanisms provided under the draft Bill to ensure that persons lacking capacity receive a prompt, fair and public hearing.**

58. Some evidence was also received by the Committee that article 3 might be contravened by the provisions of the draft Bill. It provides:

“No one shall be subjected to torture or to inhuman or degrading treatment or punishment.”<sup>44</sup>

59. The argument put forward was that there was scope under the draft Bill to treat vulnerable people contrary to their best interests and in a way which deprived them of life.<sup>45</sup>

60. Clause 4 of the draft Bill provides that any act done, or any decision made on behalf of a person lacking capacity must be done in his best interests. Furthermore, a number of safeguards are included to prevent the carrying out of degrading treatment. For example, there are restrictions on the use of the general authority to prohibit the use, or threat of force, or to restrict the liberty or movement of a person, except in exceptional circumstances.<sup>46</sup> We have however recommended that the exceptional use of, or threat of force, or the restriction of movement are limited to emergency situations and that the period of detention should be as short as possible (see chapter 8 paragraph 132). The Committee are satisfied that this additional safeguard will ensure that persons lacking capacity will be protected from being subject to degrading treatment and significant harm. In addition, and as stated in paragraph 53 above, the Committee are satisfied that the provisions of the draft Bill to do not deprive persons of the right to life.

**61. Accordingly, we are of the opinion that the arguments put to the Committee that the draft Bill violates the rights enshrined in article 3 are without merit. In agreement with the Joint Committee on Human Rights, we conclude that the draft Bill provides sufficient safeguards to ensure that the right to be free from degrading treatment is protected.<sup>47</sup>**

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<sup>43</sup> See chapter 10

<sup>44</sup> Schedule 1, Human Rights Act 1998

<sup>45</sup> Ev 433 MIB 933

<sup>46</sup> Clause 7

<sup>47</sup> Subject the recommendations of the Committee contained in this report.



## 6 Chapter 6: (Clauses 1-3) Decision-making capacity

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### Clause 1: Decision-making capacity

62. Clause 1 of the Bill sets out the concept of decision-making capacity. This is central to the draft Bill since the powers enshrined in it are triggered by a person's incapacity. The submissions we received all supported the general principle of respect for autonomy that underpins this Bill.

63. We recognise that in the case of health care decisions the Courts have determined that it is for adults to decide for themselves whether or not to have medical treatment.<sup>48</sup> For such decisions to be valid the person has to be fully informed about the decision in question, has to have the capacity to make that decision for him/herself, and has to have made the decision voluntarily.

64. We note that the only exception in current law to the principle that a competent person has a right to make such decisions for him/herself is in the case of treatment for a mental disorder where the wishes of a competent person could, under specific circumstances, still be over-ruled under the terms of the Mental Health Act, 1983. In all other situations a person's 'decision-making capacity' is the pivotal issue that determines whether his/her decision must be respected or not. The same principle of autonomy also applies to decisions outside that of health care.

65. The draft Bill states that the decision-making capacity of an individual must be presumed until demonstrated to the contrary and that capacity is both 'decision specific' and 'time' specific. The majority of the evidence we heard on this matter endorsed these principles. This 'functional' approach to capacity implies that a person may be capable of making one decision but not another (perhaps more complex) one, or may be capable of making a particular decision at one point in time but not at another. This approach to capacity has implications throughout the whole Bill, especially under the General Authority and Lasting Powers of Attorney (LPA).

**66. We agree with the definition of capacity and the additional clauses under Clause 1 of the draft Bill. We support the principle of presumption of capacity which underpins the draft Bill. We note the functional approach adopted by the draft bill when allied to Best Interests is intended to provide protection to those lacking capacity. In this context, we believe that every effort should be made in both the Bill and in the Codes of Practice to ensure that this Bill is seen as enabling rather than restricting.**

67. The only cautionary word in relation to the functional approach came from the Master of the Court of Protection, who drew our attention to problems that may be caused if the definition in the Bill refers only to specific issue capacity and makes no mention of more

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<sup>48</sup> *Re: C* [1991] 3 All ER 866; *Re: B* [2002] EWHC 429 (Fam)

general incapacity. He gave examples of the potential for people with on-going incapacity to make a series of judgments or decisions that may have disastrous consequences.<sup>49</sup> Under the existing law, a person who is deemed to lack capacity to manage and administer his/her property and affairs may come under the jurisdiction of the Court of Protection.<sup>50</sup> The purpose of the Court's jurisdiction "is to take out of the hands of that individual his or her decision-making function in relation to property and affairs."<sup>51</sup> For example, if a receiver has been given authority by the Court to take over the handling of the person's property and financial affairs, the person cannot arrange to sell any property or purchase any goods independently of the receiver, whether or not s/he has capacity to do so. This recognition of more 'general incapacity' is intended to protect the person's interests. **We recommend that the current clause 3 in the draft Bill before us becomes either clause 2 of any new draft, if our recommendations as to the inclusion of the general principle is accepted; or if not, then the current clause 3 should be clause 1 of any new draft Bill. This is because it better reflects the positive nature of the Bill's purpose and will increase confidence in the operation of this legislation.**

68. We see the need for recognising the issue of 'general incapacity' in the draft Bill in a way that will not undermine the primacy of the functional approach and have recommended accordingly. We endorse the criteria of capacity set out in Clause 2 of the draft Bill for assessing whether a person is unable to make a decision and therefore lacks capacity. But we recommend that consideration be given to recognising the issue of 'general incapacity' in the draft Bill in a way that will not undermine the primacy of the functional approach.

69. The draft Bill states in clause 1(1) that 'a person lacks capacity in relation to a matter if at the material time he is unable to make a decision for himself in relation to the matter in question because of an impairment of or a disturbance in the functioning of the mind or brain. In 1(2) it states that it does not matter whether the impairment or disturbance is permanent or temporary. In clauses 2(1) (a) to (d) the Bill sets out the conditions that need to be satisfied to determine that a person is unable to make a decision for himself. Clauses 2 (2 to 5) sets out certain other provisos that must be considered.

70. **We recommend that the Codes of Practice should state clearly that all relevant parties must use appropriate strategies to maximise the chance that persons will have the capacity to make decisions. This might include using specific communication strategies, providing information in more accessible form, or treating an underlying mental disorder to enable a person to regain capacity.**

71. We received no evidence critical of the basic criteria for determining incapacity. There was broad support for the concept that evidence of impairment in mental functioning had to be accompanied by evidence of incapacity. **We endorse the functional approach to the determination of incapacity and the need to demonstrate 'an impairment of or a**

<sup>49</sup> Q495, Q496 (Mr Lush)

<sup>50</sup> Mental Health Act 1983, s 94

<sup>51</sup> *Masterman-Lister v Jewell and others* [2002] EWHC 417, QB at 29

**disturbance in the functioning of the mind or brain in asserting whether a person's capacity is temporary or permanent. We do not see the need to distinguish in the Bill between the temporary or potentially permanent nature of incapacity.**

72. Our witnesses generally accepted that, as stated in clause 2(2), people may make decisions seen by others as unwise but that in itself should not determine incapacity. People should be allowed to take risks. But some witnesses expressed concern about the apparently capable person who repeatedly made unwise decisions, particularly where such decisions might lead to neglect or suffering.<sup>52</sup> Others pointed out that apparently capable but vulnerable people were be easily susceptible to undue influence.<sup>53</sup> The importance of taking 'all practical steps to help a person make a decision' was also emphasised.<sup>54</sup>

73. The Making Decisions Alliance argued that capacity was rarely entirely present or entirely absent and they were concerned that insufficient time or effort might be spent seeking alternative ways of imparting information or communicating with people who might then have capacity. They emphasised that decision-making should be seen as part of a process and that interventions, such as support with communication and the provision of accessible information, were essential.<sup>55</sup> With respect to clause 1(2) the Law Society in their evidence drew a distinction between those disorders that might lead to temporary or more permanent incapacity.<sup>56</sup>

74. We heard evidence from user organisations representing people with learning disabilities that the powers in the draft Bill might be used to restrict their freedoms and opportunities against the principles laid out in the Government White Paper 'Valuing People'. They feared that incapacity would all too readily be assumed, enabling a family member or carer to over-rule those lacking capacity.<sup>57</sup>

75. Values into Action argued that a cursory and unchallenged determination of incapacity would too readily lead into the use of the General Authority. They stressed that people with learning disabilities could invariably contribute to the decision-making process providing time and support was available to them.<sup>58</sup>

**76. We recommend that the Codes of Practice should set out clearly the need for evidence on both 'impairment of or disturbance in mental functioning' and of lack of capacity, as defined in the draft Bill, and the appropriate means of determining that evidence in the best interests of the person concerned so that the criteria against which an appeal might be judged are transparent.**

**77. We recommend that the Codes of Practice should make clear that those acting under the General Authority or an LPA must appreciate the concept of**

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<sup>52</sup> Ev 183 MIB 1049 para 10, Q495, Q496 (Mr Lush), Q483 (Mr Dixon)

<sup>53</sup> Ev 140 MIB.679, Qs506-8 (Mr Lush), Q590 (Mr Raymond), Ev 200 MIB.1210

<sup>54</sup> Ev 30 MIB 950 para 4.3.1-2, Ev 475 MIB 1057 paras 3.1.2-5

<sup>55</sup> Q93, Q101 (Ms. Willmington)

<sup>56</sup> Q557, Q558 (Mr Clements)

<sup>57</sup> Ev 230 MIB.733, Q647 (Ms Aspis), Q654 (Mr MacGiven), Q658 (Mr Lee)

<sup>58</sup> Ev 230 MIB.951



capacity/incapacity and be fully aware of the responsibilities thus placed on them when carrying out or assisting decision-making on behalf of any person who is considered incapacitated. While it would be unreasonable to expect all those acting under the General Authority to have the necessary knowledge to determine that person's capacity to make any given decision, it is reasonable to expect them to take appropriate advice and have appropriate people to assist them where necessary. The Codes of Practice must set out a framework on these matters which is readily understandable to lay persons.

78. We considered carefully the dilemma created when a person with apparent capacity was making repeatedly unwise decisions that put him/her at risk or resulted in preventable suffering or disadvantage. We recognise that the possibility of over-riding such decisions would be seen as unacceptable to many user groups. Nevertheless, we suggest that such a situation might trigger the need for a formal assessment of capacity and recommend that the Codes of Practice should include guidance on:

- whether reasonable doubt about capacity and the potentially serious consequences of not intervening indicated the need for an appropriate second opinion;
- circumstances in which the statutory authorities should be responsible for providing a level of support as a safeguard against abuse; and
- where there was genuine uncertainty as to capacity and an urgent decision was required to prevent suffering or to save life, the benefit of doubt would be exercised to act in that person's best interests in relation to any assessment of capacity.

## 7 Chapter 7: (Clause 4) Best interests

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### The concept of "best interests"

79. Clause 4 of the draft Bill seeks to establish the common-law principle that any act done for, or any decision made on behalf of a person who lacks capacity must be in the person's "best interests". This principle has become well-established and developed by the courts in cases relating to incapacitated adults. Under the draft Bill, capacity to do the act or make the decision in question must first be assessed and Clause 4 only comes into play once it has been established that the person lacks capacity. It then sets out a number of basic common factors to which "regard must be had" in all situations when determining what is in an incapacitated person's best interests.

80. The submissions received by the Committee have broadly supported the view that the factors listed in Clause 4 are indeed particularly relevant and important in guiding decision-making on behalf of people lacking capacity to make their own decisions. However, some witnesses<sup>59</sup> objected to the term "best interests" itself, sharing the views

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<sup>59</sup> Ev 190 MIB 564, Ev 11 MIB 989

expressed by the Scottish Law Commission<sup>60</sup> that the concept of best interests is too vague and, since it was developed in the context of child law, too paternalistic to be applied to adults. The Making Decisions Alliance<sup>61</sup>, while supporting a best interests approach, was concerned that the principle of best interests had been developed primarily in case law concerned with the provision of medical treatment<sup>62</sup> and the term was therefore too often linked to clinical and healthcare considerations which may not be relevant in relation to other types of decisions.

81. We have already expressed the view that greater clarity could be achieved by setting out, at the start of the Bill, a statement of general principles to govern all actions and decisions taken under the new legislation (see paragraph 3, Chapter 3). Some witnesses, including the Law Society of Scotland<sup>63</sup> supported by the Law Society of England and Wales<sup>64</sup>, expressed the view that clearly stated principles such as those set out in Section 1 of the Adults with Incapacity (Scotland) Act 2000 (AWI Act) should include all the factors involved in determining best interests and would therefore replace the need for the term itself and the definition contained in Clause 4.

82. However, other witnesses believe that where a person is incapable of making his/her own decision, “the only viable approach is a best interests approach”.<sup>65</sup> We heard evidence that the concept of best interests has been usefully developed by the courts and that its inclusion in statute would assist in promoting awareness and good practice, thereby ensuring some consistency in approach.<sup>66</sup> Indeed, many submissions appear to support this view, although several commentators have suggested ways in which the definition could be improved or the scope of best interests could be extended (see paragraph 84 below), in particular to emphasise the need to identify the issues most relevant to the individual who lacks capacity (as opposed to the decision-maker or other persons) and the particular circumstances relating to the decision in question.

**83. We take the view that the general principles set out at the start of the Bill should confirm that any act done for, or any decision made on behalf of a person who lacks capacity must be in the person’s “best interests”, and agree that statutory guidance on determining best interests should be included in the Bill.**

### ***The definition and scope of best interests***

84. In its report on Mental Incapacity, the Law Commission acknowledged that “no statutory guidance could offer an exhaustive account of what is in a person’s best interests, the intention being that the individual person and his or her individual circumstances should always determine the result”.<sup>67</sup> Instead, it recommended that statute should set out

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<sup>60</sup> Scottish Law Commission Report on Incapable Adults, para 2.50

<sup>61</sup> Ev 30 MIB 950, Ev 85 MIB 1180

<sup>62</sup> See for example Re MB [1997] 2 FLR 426, Re S [2000] 2 FLR 389

<sup>63</sup> Ev 1 MIB 990

<sup>64</sup> Ev 203 MIB 1030 Qs 547-552 (?)

<sup>65</sup> Ev 416 MIB 1192

<sup>66</sup> Ev 190 MIB 564

<sup>67</sup> Law Commission No 231 (1995), para 3.26

a checklist of common factors which must always be taken into account. The checklist set out in Clause 4 is therefore intended to be the minimum necessary in any determination of best interests.

85. We agree that no list of ‘best interest’ factors can ever be comprehensive or applicable in all situations. We therefore endorse the approach recommended by the Law Commission that a checklist of common factors to be considered in all cases should be set out in statute. However, it should be made clearer in the Bill that, in addition to these common factors, all other matters relevant to the particular incapacitated individual and the particular decision must also be considered.

86. Several submissions suggested various ways in which the statutory checklist could be improved. A number of suggestions are considered below:

### *Benefit*

Several witnesses suggested that the concept of “benefit” contained in the Scottish AWI Act would be a helpful addition to the best interests checklist.<sup>68</sup> The AWI Act stipulates that “There shall be no intervention ... unless that intervention will *benefit* the adult and that such benefit cannot reasonably be achieved without the intervention.”<sup>69</sup> The term “benefit” is not defined, but guidance suggests that the intervener must weigh the intervention against the benefit to the incapable adult – the more serious the intervention, the greater the benefit that should have to result from it. The advantage of this requirement is that it places the focus firmly on the incapable adult and gives priority to his/her needs, which is an important consideration when the formal interventions available under the AWI Act are invoked. The disadvantage is that, if applied too rigidly, it may not allow consideration of other relevant factors (such as those affecting carers) which may be an important consideration in meeting the person’s needs or addressing their particular circumstances. This is a key consideration already applied by the courts.<sup>70</sup> **In the context of the comprehensive decision-making framework created under the draft Bill, we concluded that the concept of benefit may be too prescriptive if added to the checklist.**

### *Best ‘personal’ interests*

87. The Making Decisions Alliance<sup>71</sup> invited us to consider a proposal originally put forward by the Law Society<sup>72</sup>, to adopt the phrase ‘best *personal* interests’ in order to stress that priority should be given to identifying those issues relevant to the incapacitated individual, and what s/he would have wanted to achieve, rather than to the decision-maker or other person. We are pleased that in correspondence with the Chairman, Lord Filkin

<sup>68</sup> Q16 (Mr Ward)

<sup>69</sup> Adults with Incapacity (Scotland) Act 2000, s 1(2)

<sup>70</sup> For example, in the case of *Re Y* [1996] 2 FLR 787, the court held that it was in an incapacitated person’s wider best interests as a family member to allow her bone marrow to be used to treat her sibling, even though the treatment was of no clinical benefit to her personally.

<sup>71</sup> Ev 30 MIB 950 and Qs 93-97, 155-157, 167-168

<sup>72</sup> Law Society, Response to ‘Who decides?’ (1998)



has confirmed that “Our intention is precisely to give primacy to the personal interests of the individual. ... This is, perhaps, something that could be made more explicit in a statement of principles at the head of the legislation”.<sup>73</sup> Given that Clause 4(1) already requires that any act must be done or decision made “in *the person’s* best interests”, **we concluded that the addition of the word personal to best interests would not provide any better clarification and indeed might cause confusion.**

### ***Primacy of interests***

88. One way of focusing on the needs and wishes of the incapacitated person might be to prioritise the best interests checklist or to weight particular factors, for example by giving primary (or paramount) consideration to the individual’s subjective wishes and judgements where these could be ascertained. We received conflicting evidence on this issue. Organisations and self-advocacy groups of people with learning difficulties<sup>74</sup> clearly felt that their views would not be given sufficient weight under the Bill’s provisions as currently drafted. However, other witnesses felt that any weighting would make it impossible to balance the need to promote autonomy of the individual with the need to provide protection and appropriate care. In particular, witnesses with particular concerns about end-of-life decisions felt that medical or clinical need directed to preserving life and promoting good health should take priority.<sup>75</sup> Carers UK felt a distinction should be drawn between family and paid carers and the views of family carers be given priority over paid carers and professionals<sup>76</sup> while Care UK, an independent provider of health and social care services, suggested that best interests should be specifically linked to maintaining independence, which would enable care professionals seeking to maximise opportunities for developing independence to override the wishes of over-protective parents or relatives of people lacking capacity.<sup>77</sup>

89. We acknowledge that consideration of best interests requires flexibility, by allowing and encouraging the person to be involved to the fullest possible extent but also enabling the decision-maker to take account of a variety of circumstances, views and attitudes which may have a bearing on the decision in question. This flexibility is particularly important in cases of partial or fluctuating capacity. Determining best interests is a judgement, requiring consideration of what will often be conflicting or competing concerns, while seeking to achieve a consensus approach to decision-making. **We do not recommend any weighting or giving priority to the factors involved in determining best interests. It will be important for the Codes of Practice to provide guidance on how judgements about best interests may be reached, particularly where there are conflicting or competing concerns.**

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<sup>73</sup> Ev 284 MIB 1221

<sup>74</sup> Ev 228 MIB 778, Ev 226 MIB 71

<sup>75</sup> Ev 141 MIB 183, Ev 144 MIB 561, Ev 135 MIB 561

<sup>76</sup> Ev 335, MIB 771

<sup>77</sup> Ev 245 MIB 1202

## Values

90. The Medical Ethics Alliance<sup>78</sup> suggested to us that the factor involving the need to consider the incapacitated person's "past and present wishes and feelings" should also contain reference to that person's *values*. Others<sup>79</sup> suggested that specific reference should be made to social, psychological, cultural, spiritual and religious issues. It is anticipated that the need to consider a wide range of issues, in particular religious and cultural concerns, will be spelt out in the Codes of Practice. **We seek reassurance that the form of words used in the Bill will require a person's values to be given due weight.**

## Human rights

91. Professor John Williams<sup>80</sup> has suggested that the term "best interests" could be replaced with "in the interests of promoting the human rights of the person concerned" in order to require decision-makers to carry out a "human rights calculation", for example in considering the person's right to a private life versus the right not to be subjected to inhuman or degrading treatment. Any public authorities (or their employees) carrying out duties or exercising powers under the new Act will in any event have to ensure they act in compliance with the Human Rights Act 1998. **We considered it would be too onerous on relatives, carers and other informal decision-makers to require an understanding of human rights legislation when determining best interests. The Codes of Practice and any Departmental guidance issued to the general public should explain the relevant human rights considerations.**

## Consultation with others

92. Both the AWI Act and the draft Bill indicate the need to consult with other relevant people and the groups specified are similar, with the exception that the Bill has no equivalent of "nearest relative" and allows the person concerned to nominate people to be consulted. The AWI Act does not specify the type of views of others which must be taken account of, while the draft Bill limits the consultation with others to obtaining views on the past and present wishes and feelings of the person and what factors that person might have taken into consideration if able to do so. The Law Commission had suggested that concerned relatives and carers should also be able to express a view as to what might be in the person's best interests in relation to the decision in question.<sup>81</sup> Although this recommendation was accepted by the Government in 'Making Decisions'<sup>82</sup>, it has not been carried forward in the draft Bill. Several submissions stressed the need for families, civil partners and carers to be fully consulted and involved in decisions about best interests.<sup>83</sup> **We consider that specific provision should be made to confirm that consultation with**

<sup>78</sup> Ev 141 MIB 183

<sup>79</sup> Ev 144 MIB 561, Ev 100 MIB 817, Ev 364 MIB 822, Ev 203 MIB 1030, Ev 165 MIB 1206

<sup>80</sup> Ev 190 MIB 564, Qs 522-527

<sup>81</sup> Law Commission Report 231 (1995), paras 3.33-3.36

<sup>82</sup> Lord Chancellor's Department, *Making Decision: The Government's proposals for making decisions on behalf of mentally incapacitated adults* (1999)

<sup>83</sup> Ev 243 MIB 61, Ev 335 MIB 771

people close to the incapacitated person will include consideration of their views on what is likely to be in that person's best interests. In advance of the legislation anticipated on the status of civil partners we would expect the expression 'people close to' to include civil partners.

### *What is required of the decision-maker?*

93. In addition to the requirement to show benefit, the AWI Act also *requires* any intervention to be the least restrictive option in relation to the freedom of the adult, and that "*account shall be taken of*" the views of the adult and of relevant others. The draft Bill uses the weaker formulation "*have regard to*" the various factors in the checklist, following the conclusion reached by the Law Commission that any more forceful form of words could become over-prescriptive and detract from "best interests" as the pre-eminent consideration.<sup>84</sup>

94. A number of submissions<sup>85</sup> indicated that the Bill, as currently drafted, was more a charter for carers and other decision-makers rather than protecting the interests of people lacking capacity. The need to make decision-makers more accountable for their actions would seem to indicate the need for a stronger form of words specifying more clearly their duties in relation to determining best interests. **We recommend that the drafting of Clause 4 be amended to impose a requirement on decision-makers to seek the least restrictive option, and to specify that, in determining best interests, account must be taken of all the factors set out in the checklist.**

### *Least restrictive option*

95. We were impressed with that part of the AWI Act principles which confirms that intervention into the affairs of an incapacitated person should only be contemplated where it is absolutely necessary and the purpose for which that intervention is needed cannot be achieved in any other way.<sup>86</sup> The need for an equivalent 'no-intervention' provision in the Bill was expressed by the Law Society and other witnesses.<sup>87</sup> In deciding whether permission should be granted to refer a case to the Court of Protection, Clause 40(3) of the draft Bill would require the court to consider the benefit to the person of the proposed order or directions, and whether the benefit can be achieved in any other way than court intervention.

96. In relation to all decisions made on behalf of a person lacking capacity, both the AWI Act and the draft Bill<sup>88</sup> specify the need to choose the option that is least restrictive of the person's freedom of action. **We take the view that a requirement on decision-makers to seek the least restrictive option would involve having to consider whether any**

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<sup>84</sup> Law Commission No 321 (1995) Para 3.28, footnote 47.

<sup>85</sup> Ev 226 MIB 71, Ev 228 MIB 778, Q427 (Mr Dixon)

<sup>86</sup> Section 1(2)

<sup>87</sup> Q551 Ev 209; Q553 Ev 210; Ev 33, para 3.4

<sup>88</sup> Clause 4(2)(e)



intervention at all was necessary. We therefore see no need for a specific “no intervention” provision other than in relation to court proceedings.

### ***Standard of conduct / Duty of care***

97. The Master of the Court of Protection suggested that there are inadequacies in the approaches of both the AWI Act and the draft Bill, in that neither places sufficient obligations and duties on substitute decision-makers.<sup>89</sup> Instead of imposing a duty to act in a person’s best interests, the Master has suggested that:

“there should be a comprehensive statement of the standard of conduct required of everyone who acts or makes decisions on behalf of persons without capacity, and if their behaviour falls below those standards it should be possible for the court to remove them as attorneys or deputies, or as the case may be, and if their conduct is criminal, they should face the prospect and consequences of prosecution”.<sup>90</sup>

98. The Master suggested a number of specific obligations and duties which should be set out in any such standard of conduct.<sup>91</sup> We agree that it would be appropriate to impose a standard of conduct on formal decision-makers appointed under a Lasting Power of Attorney or a court order. **We strongly recommend that the requirements of a standard of conduct be included in the Codes of Practice aimed at those exercising formal powers under the Bill. We also recommend that the Department should issue clearly understandable guidance to informal decision-makers on the standards of conduct expected.**

99. Witnesses before the Committee<sup>92</sup> were unclear as to whether decision-makers acting under the Bill’s powers would be subject to a common law duty of care. **We seek reassurance that a common law duty of care would apply to all decision-makers under the Bill and ask that consideration be given to imposing a duty of care through express statutory provision. Here, too, the Department will need to issue guidance to informal decision-makers on the expected standards of conduct.**

### ***Reasonable belief***

100. The need to determine and act in accordance with the incapacitated person’s best interests will apply in relation to all decisions made under the new Act, extending from informal decisions to court based powers. Where there is a need for court intervention, the Court will clearly require formally documented evidence that the person lacks capacity to make the decision in question and will consider evidence from a range of sources as to what course of action might be in the person’s best interests. However, in many day-to-day situations, such formality is neither required nor appropriate and in emergency cases may not be possible. Clause 4(4) is intended to deal with these types of situations by confirming

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<sup>89</sup> Ev 183 MIB 1049

<sup>90</sup> Ev 185 para 22

<sup>91</sup> Ev 184, para 13

<sup>92</sup> Q511 (Mr Lush), Ev 135 MIB 781, Ev 419 MIB 1193

that the requirement to act in a person's best interests will be complied with if the decision-maker "reasonably believes that what he does or decides is in the best interests of the person concerned".

101. We heard evidence<sup>93</sup> that while the notion of "reasonableness" may be familiar to lawyers, it is not so familiar to other decision-makers who might disregard the best interests checklist and justify their actions from their own subjective viewpoint of what is reasonable.

102. The Making Decisions Alliance<sup>94</sup> suggested that a decision-maker should be required, "on the basis of objective evidence", to show that his/her belief that s/he was acting in the person's best interests was in fact reasonable. The Law Society pointed out that there is much case law on the issue of reasonableness and argued that "whether the reasonableness here is an objective or a subjective test should be made clear on the face of the Bill."<sup>95</sup> In oral evidence, the Law Society<sup>96</sup> suggested that a similar formulation of words to that used in the Disability Discrimination Act 1995<sup>97</sup> might be the most appropriate. This would state that best interests would be complied with if, in the decision-maker's opinion, what s/he does or decides is in the person's best interests and it is reasonable in all the circumstances of the case for the decision-maker to hold that opinion. We are sympathetic to the need for compatibility between different legislation affecting similar groups of people, such as those lacking capacity. Lord Filkin has confirmed to us that "This must be an objective belief".<sup>98</sup> **We recommend that the Codes of Practice should explain more clearly the circumstances in which reasonable belief should be relied upon.**

## 8 Chapter 8: (Clauses 6-7) The General Authority

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103. The draft Bill follows the recommendation of the Law Commission that future legislation on mental incapacity should include a 'general authority to act reasonably'.<sup>99</sup> For the large number of people who would be unlikely to have made provision for their incapacity through the formal mechanisms proposed in the Bill (advance decisions or LPAs), the operational reality of the general authority is likely to be crucial. The intention of providing a 'general authority' would be to clarify the circumstances in which actions and decisions could be taken on behalf of adults who lack capacity without obtaining formal powers, and to include such 'informal' decision-making within the statutory framework set out in the Bill.<sup>100</sup> We support this objective, but we are uncertain whether

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<sup>93</sup> See for example The Law Society Ev 205, para 6, Making Decisions Alliance Ev 34, para 4.4.1 and oral evidence from both organisations

<sup>94</sup> Q102 (Mr Foster)

<sup>95</sup> Ev 224 MIB 1215, para 4

<sup>96</sup> Q595, Q599

<sup>97</sup> Disability Discrimination Act 1995, s 20(3)

<sup>98</sup> Ev 284 MIB 1221

<sup>99</sup> Law Commission Report 231, 1995, Part IV

<sup>100</sup> CM 5859-II page 8

the general authority, as currently drafted, provides sufficient protection to people lacking capacity.

### ***The rationale behind creating a 'general authority'***

104. It is the right of competent adults to make decisions concerning their own lives. Such decisions might include where to live, what to wear, what to eat, what to spend money on, who to be friends with and whether or not to seek and accept medical advice. The decisions made by an individual at a particular point in time are likely to be influenced by factors relating to that individual and their circumstances. Under our present law, the competence of an adult to make a decision cannot be challenged if there is no evidence of any impairment or disturbance in their mental functioning. No one else can make decisions on behalf of another competent person<sup>101</sup> and to force an alternative, for example by physical means, would be an assault.

105. A person's mental functioning may be affected by mental or physical illness, a head injury or their consumption of alcohol or other drugs. These factors could limit the person's ability to take decisions for themselves. At present, guidance on who should undertake decisions or actions on behalf of that person is absent from statute. Common law has therefore developed to fill the 'gap'. The case of *re F*<sup>102</sup> confirmed that where an action taken on behalf of an individual who lacked the capacity to consent to that action was necessary, reasonable and in their best interests, that (otherwise unlawful) action could be judged lawful under the 'principle of necessity'. The principle of necessity is *not* equivalent to having consent but constitutes a defence if an action is subsequently challenged.

A doctor who physically examines and subsequently operates on an unconscious person can argue, if later challenged, that although the patient had not given consent to the procedures, their action was necessary to save their life. Similarly, a nurse who undresses and washes a person with advanced dementia can argue that this action was necessary for their health.

106. Despite the existence of the principle of necessity, the Law Commission report identified uncertainties in the present law regarding informal substituted decision making.<sup>103</sup> Much of the evidence we received also made clear that the law regarding informal substituted decision making is not widely understood.<sup>104</sup> The Making Decisions Alliance for example, told us:

<sup>101</sup> Other than in specific situations where the person has previously authorised it, for example in setting up a joint bank account or in granting a power of attorney.

<sup>102</sup> [1990] 2 AC 1

<sup>103</sup> Law Commission Report 231, part IV

<sup>104</sup> Ev 191 Q513, Ev 208 Q545



“...many organisations representing carers have been concerned that they are unsure about how to make decisions which represent the views of people who lack capacity and they want clarity about what day-to-day decisions they can make without going to the courts for formal authorisation, so the general authority is positive in the sense that it will dispel the doubts and confusion from carers about what they can do.”<sup>105</sup>

107. We heard evidence that reliance on the common law is not an adequate alternative to legislation in this area, not least to ensure compliance with the Human Rights Act.<sup>106</sup> The present common law approach does not provide adequate protection for those providing support to individuals who lack capacity. The absence of statute has meant that there has been no formal guidance on informal substituted decision making, as would be provided by a Codes of Practice. Nor are the duties and responsibilities of those making decisions on behalf of others immediately apparent. Furthermore in the absence of any ready means of appeal, the rights of people who lack capacity are not adequately protected.<sup>107</sup> By creating a general authority, the draft Bill codifies in statute what has become practice under common law, incorporating the principle of respect for the autonomy of a capable person. The intention is to clarify the circumstances in which actions and decisions can be taken on behalf of adults who lack capacity without obtaining formal authorisation, while holding decision-makers accountable for their actions. It is not intended that the general authority would convey any new or additional powers on anyone acting on behalf of an incapacitated person that they would not already have under existing statute or the common law. Thus, under the general authority it would be lawful for a person to act for someone who lacks capacity where in all the circumstances it is reasonable for the person to take that particular action and the act is in the incapacitated person’s best interests.

A doctor wishing to examine someone would first be expected to determine the person’s capacity to consent to examination. If the person lacked capacity to consent then the doctor could lawfully examine them if it was reasonable and in that person’s best interest to do so. As is currently the case, no one else has the right to consent to medical treatment on behalf of the incapacitated person but the ‘general authority’ would provide the legal authorisation for the doctor to carry out the examination in the absence of consent.

A carer in a group home regularly goes shopping with Mr G., a man with learning disabilities. Mr G likes to look after his own money but sometimes gets into arguments over how much he needs to give to the shop keeper. He can recognise coins but he is uncertain how that relates to the price of the goods and he also becomes very confused over change. He has been known to give away more money than he should and also to argue because the shop keeper requires more to fully pay for the goods. His carer is uncertain how to resolve this dilemma. Given that it is clear on assessment that Mr G lacks the

<sup>105</sup> Q179 (Mr Kramer)

<sup>106</sup> Ev 190 MIB 564

<sup>107</sup> As illustrated by cases such as *re C* [1994] 1 All ER 819 and *R v Bournewood Community and Mental Health NHS Trust ex parte L* [1998] 3 All ER 289

capacity to make such financial decisions the general authority would allow the carer to ensure that the proper price was paid for the goods providing it was in Mr G's best interests. In deciding what was in his best interests the carer would have to take due note of the fact that Mr G wished to buy the goods in question and to work with Mr G so that he felt involved in the transaction. As set out in the Codes of Practice any intervention should be the least restrictive and the most enabling. Mr G should hold his own money and be supported in the choosing and budgeting process. The carer would also be enabled through the General Authority to ensure that Mr G was not taken advantage of or inappropriately refused to pay.

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Mrs R is caring for her husband who has Alzheimer's disease. He has become increasingly confused and forgetful. He is neglecting himself and can be at risk as he wanders at night and walks out of the house saying he is going to work. He sometimes goes for respite care at a Local Authority run rest home. His level of confusion varies but he is often uncertain where he is or who members of his family are. His wife and family have to provide for most of his day to day needs and sometimes they have to stop him leaving the house for his own safety. Such actions are acceptable under the General Authority as it is clear that Mr R has lost the capacity to make these day to day decisions for himself due to the presence of Alzheimer's disease, and it is in his best interests that his basic needs are met and that he is prevented from wandering out of the house unaccompanied. The Codes of Practice provides guidance for the family and also to the Local Authority home staff who need to balance respect for his wishes, as far as they can be ascertained, with their duty to care for him in manner that is the least restrictive and most respectful of his and his family's wishes.

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108. We are convinced that the present situation regarding informal substituted decision making would benefit from clarification, but very few witnesses expressed unqualified support for the general authority as a means to achieve this goal. We have heard evidence of a wide range of concerns regarding the provision which we discuss in more detail below.

### ***Concerns arising from drafting and terminology***

109. A number of the concerns which have been brought to our attention seem to be premised on a misunderstanding of the general authority as it is set out in the draft Bill. The extent of the misunderstandings apparent in the evidence we have received suggests that the drafting of this provision is not sufficiently clear. Many interested parties appear to be under the erroneous impression that the general authority would be assumed by a single individual who would then take all decisions on behalf of an incapacitated individual.<sup>108</sup> In fact the general authority is for the relevant person, in the context of a specific decision or action, at a particular point in time, so long as it is reasonable for that person to act. Others

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<sup>108</sup> Ev 228

have suggested that the general authority may be used by carers to justify taking decisions for which they would otherwise need formal authorisation.<sup>109</sup> In fact the general authority is not intended to convey any new powers on anyone but rather to clarify the uncertain principle of 'necessity'.<sup>110</sup>

110. We have come to the conclusion that the term 'general authority' itself has contributed to the misinterpretations apparent within the evidence we have received. The word 'authority' implies an imposition of decision making upon an incapacitated individual rather than an enabling process designed to enact decisions taken in their best interests. This may have contributed to perceptions of the general authority as likely to promote 'overpaternalistic attitudes'<sup>111</sup> towards incapacitated individuals. We are convinced that semantic issues are important in affecting public perceptions of the draft Bill as well as in determining legal interpretations of the provisions it contains.

**111. We recommend that clauses 6 and 7 be redrafted to clarify the legislative intent of the general authority, in order to counter what appear to be widespread misunderstandings of the concept and its purpose. It might also be helpful for the Department to consider an alternative to the term 'general authority' which would avoid its misleading connotations and clarify that it is intended to convey permission to act in the incapacitated person's best interests in circumstances currently covered by the Common Law.**

112. Clause 6(1) permits the general authority to be relied upon by anyone 'providing any form of care for another person'. Several witnesses expressed concern that the Bill provides no definition of what such 'care' would entail.<sup>112</sup> The need to define the term 'care' is particularly relevant to the circumstances of day-to-day decisions taken (under the general authority), especially by informal carers or other non-professionals. **We recommend that the Department should clarify the term 'care' in clause 6 (1) and in any guidance given under the Codes of Practice.**

**113. In addition, we recommend that a sustained and comprehensive training programme for professionals, and a public information campaign for informal carers should be implemented, in order to provide these groups with an accurate understanding of the general authority.**<sup>113</sup>

114. We feel however, that even if the drafting and terminology of the general authority was clarified, a number of substantive areas of concern would remain. These areas of concern (discussed below) include:

- Best interests
- Reasonable belief

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<sup>109</sup> Ev 10 Q41, Ev 12, Ev 56 Q100

<sup>110</sup> Law Commission No 231 (1995) para 4.2

<sup>111</sup> Ev 16 MIB 991

<sup>112</sup> Ev 12, Ev 35 para 4.5.7, Ev 115 Q313

<sup>113</sup> Ev 36 para 4.5.12



- The scope of the general authority
- The adequacy of safeguards
- Further exclusions
- Dispute resolution mechanisms
- Use of force

### ***Best interests***

115. We have already made a number of general recommendations about the formulation of the concept of best interests in clause 4 (chapter 7). Under clause 6(6), any decision or act taken under the general authority must be in the best interests of the incapacitated individual. We heard evidence that the concept of best interests was not given sufficient priority within the clause.<sup>114</sup> **We recommend that in re-drafting clause 6 the Department should emphasise the over-riding importance of the best interests of the person concerned, as defined in clause 4.**

116. Organisations and self-advocacy groups of people with learning difficulties told us they are concerned that the general authority would prioritise the protection of carers over the best interests of incapacitated individuals.<sup>115</sup> Witnesses from the Association of Directors of Social Services described the general authority as a ‘carer’s charter’ which could reverse the progress made in person-centred planning in recent years.<sup>116</sup> We are of the opinion that the intent of this Bill is to ensure that all those with impairments in mental function that might affect decision-making capacity have the right to make those decisions that they have the capacity to make and to have those decisions respected. In the case of those decisions and situations where such capacity is lacking, the person concerned should be involved, as far as it is possible, in helping to determine the outcome of any decisions made by others, so as to ensure that it is in their own best interests and that it gives due respect to any wishes they have expressed in the present or the past. **We are concerned that the provision of the general authority should not undermine the ‘enabling’ ethos of the draft Bill.**

### ***Reasonable belief***

117. As discussed in paragraphs 100-102 above, the notion that decisions and actions may be undertaken under a standard of ‘reasonable belief’ has caused considerable concern.<sup>117</sup> Clause 6(1) states that the general authority may be exercised by a person who ‘reasonably believes’ that an individual lacks capacity in relation to a specific decision. Although ‘reasonableness’ is a commonly used legal concept, we heard evidence of concerns that the

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<sup>114</sup> Ev 182 para 7(a)

<sup>115</sup> Ev 231 paras 5 and 9, Ev 232 Q646 (Mr Lee)

<sup>116</sup> Ev 182 MIB 1213

<sup>117</sup> See for example Q194 (Mr Kramer) and Ev 35, para 4.5.5

concept might be misunderstood by lay persons acting under the draft Bill.<sup>118</sup> We recommend that a reasonable belief should be objectively held.

### ***The scope of the general authority***

118. We share the concern expressed by many of our witnesses at the lack of guidance on the face of the Bill as to the full scope of the general authority.<sup>119</sup> From the examples given in the ‘Commentary and Explanatory notes’ accompanying the Bill<sup>120</sup> it seems that the two key factors determining whether an act or decision would be reasonable under the general authority are its significance and the length of time in which it must be undertaken.<sup>121</sup> Where a decision is of relatively low significance (deciding what to wear or what to have for breakfast) it would be reasonable for it to be taken under the general authority providing there was a reasonable belief that the person lacked the capacity to make the decision and the decision was in their best interests. Such a decision could reasonably be taken however long was available for it to be undertaken. Where a decision is of more significance (where to live or whether to undergo a medical procedure), the time available for the decision to be undertaken becomes relevant. Significant decisions may only be taken under the general authority if there is insufficient time to seek formal decision-making authority. Thus for example, a doctor who amputated a limb from a temporarily incapacitated individual in order to save their life could retrospectively claim to have acted under the general authority.

**119. We strongly recommend a redrafting of the clauses concerning the general authority in order to clarify that its use is intended to be limited to day-to-day decision-making and emergency situations.**

120. The lack of guidance on the face of the Bill makes it very difficult to determine where the boundaries fall between the general authority and the formal powers provided within the Bill. As the Making Decisions Alliance told us,

“with the general authority being so broad, we do not really see many situations where a family or carer would feel the need to become a deputy. That is a problem which again is a reason why the general authority needs to be more circumscribed.”<sup>122</sup>

121. We heard evidence that the general authority would be open to significant misuse if the concept and its scope were not better defined.<sup>123</sup> Many of the concerns centred around the potential financial abuse of incapacitated individuals.<sup>124</sup> It was suggested that such abuse could be limited by restricting the amount of money which could be used or invested

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<sup>118</sup> Ev 206, para 6 Ev 34, para 4.4.1

<sup>119</sup> See for example Ev 99 Q281, Ev 35 para 4.5 Q401

<sup>120</sup> CM 5859-II

<sup>121</sup> Q181 (Mr. Broach)

<sup>122</sup> Q205 (Mr. Broach)

<sup>123</sup> Q33, Q434, Qs 617-8

<sup>124</sup> Ev 11 MIB 584, Ev 183 MIB 989, Ev 183 MIB 1049

on behalf of an incapacitated individual and, for example, excluding the sale of their property<sup>125</sup> (see para 129 for our recommendations on exclusions from the general authority).

122. The question of the scope of the general authority is complicated by the fact that the same decision might be more significant for one individual than for another. Where an individual is only capable of making relatively simple choices, these decisions take on proportionally more significance for that individual. Witnesses from self-advocacy organisations of people with learning difficulties told us that,

“The general authority to act is open to abuse. Paid carers and relatives could say that we cannot make a choice because it is what is best for them rather than best for people with learning difficulties... Our members have told us about their relatives and paid carers bossing them about, this shows it is unwise to put our faith in these people to really allow us to make our own choices.”<sup>126</sup>

123. Under the general authority it would be relatively easy for someone to take ‘day to day’ decisions on behalf of an incapacitated individual who in fact could have made these decisions with proper support.<sup>127</sup> **We recommend that the Codes of Practice relating to the general authority should include a specific reminder that all practicable steps must be taken to help an incapacitated person contribute towards the process of every decision made on their behalf, however minor.**

### ***The adequacy of safeguards***

124. The general authority aims to provide a framework for informal substituted decision-making together with the associated safeguards that balance the rights and needs of people with incapacity. In the evidence we received however, concerns about the poorly defined scope of the general authority were accompanied by calls to increase the safeguards surrounding the provision, which was described variously as an ‘startling proposition’,<sup>128</sup> ‘carte blanche’<sup>129</sup> and ‘almost a blank cheque’.<sup>130</sup> Mr. Clements of the Law Society of England and Wales told us,

“The Law Society has always welcomed the general authority on the basis that there would also be a public law anti-abuse provision and we are now being asked to look at a Bill which has one without the other and we are not surprised that a number of organisations are concerned because it appears slightly lopsided.”<sup>131</sup>

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<sup>125</sup> Q584 (Mr. Clements)

<sup>126</sup> Q646 (Mr Lee)

<sup>127</sup> We have already recommended that a set of ‘general principles’ should be included at the start of the bill, setting out the fundamental principles which must always be taken into account when operating under the Bill. We believe that the inclusion of clause 1(3) amongst these principles will help prevent the general authority being misused in this manner.

<sup>128</sup> Q17 (Mr Ward)

<sup>129</sup> Q104 (Mr McCulloch)

<sup>130</sup> Q584 (Mr Clements)

<sup>131</sup> Q594 (Mr Clements)



Mr. Ward of the Law Society of Scotland told us he was ‘pretty sure’ that if the general authority were to be introduced as it stands,

“you would have lots of litigation for at least a decade... In some ways if there was not lots of litigation I would be even more worried because people would just be going ahead and using the general authority in all sorts of situations, appropriate or inappropriate, without challenge.”<sup>132</sup>

125. It was felt that it would not be easy for individuals acting under the general authority to be held accountable for their actions.<sup>133</sup> Various witnesses proposed ways of remedying this situation. The Making Decisions Alliance suggested that there should be a requirement for the general authority to be ‘triggered’ as part of a case conference or review discussion, but this proposal seems to misunderstand the nature of the general authority (see paragraphs 109-111 above). The Association of Directors of Social Services suggested that local authorities should have stronger powers, or even a statutory duty, to intervene in cases where there was concern over actions taken under the general authority.<sup>134</sup> Other witnesses suggested that individuals undertaking actions under the general authority should be required to keep records of their actions.<sup>135</sup> Professor Williams for example, suggested a requirement to keep simple pro forma accounts could be placed upon those acting under the general authority.<sup>136</sup> It seems to us that such a requirement would be overly bureaucratic for carers engaged in the day-to-day care of incapacitated individuals. It is also difficult to see how such requirements could be enforced without the introduction of a formal system of monitoring. **We conclude that the Codes of Practice accompanying the draft Bill should emphasise that all persons undertaking actions or decisions under the general authority must be aware that they may subsequently be called upon to justify their actions. They should therefore maintain sufficient records in order to be able to show that their actions were reasonable and in the best interests of the person in question.**

126. The Law Commission’s recommendations included detailed proposals for the independent supervision of medical and research procedures involving people lacking capacity.<sup>137</sup> For example, it was proposed that a second opinion should be required for specified serious or controversial treatment decisions (for example abortion), in a similar manner to the requirements under the Mental Health Act.<sup>138</sup> Responding to this proposal, Lord Filkin told us,

“The Code of practice will give detailed guidance on the circumstances where a doctor or other health professional should obtain a second opinion. However, I don’t

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<sup>132</sup> Qs.40-41

<sup>133</sup> Ev 196 Q532-3, Ev 231 para 5(d)

<sup>134</sup> Q464 (Mr Collingridge)

<sup>135</sup> Q179 (Mr Kramer)

<sup>136</sup> Ev 190 MIB 564

<sup>137</sup> Law Commission No 231 Part VI

<sup>138</sup> Under the Mental Health Act (1983) second opinions are required for specific forms of treatment for mental disorder (for example electro-convulsive therapy) or prolonged treatment for patients detained under the Act who are incapable or unwilling to consent.

think that an actual requirement for this to happen in certain circumstances would be either achievable or desirable on the face of the Bill itself.”<sup>139</sup>

**127. We disagree with Lord Filkin’s assessment. We recommend that consideration be given to imposing a statutory requirement for an independent second medical opinion to be sought in relation to the need for serious or invasive forms of medical treatment.**

**Furthermore we conclude that greater availability of advocacy services would provide a counter to the potential for an excessive or inappropriate use of the general authority**<sup>140</sup>

### ***Further exclusions***

128. Some witnesses felt there were other kinds of decision which should be included amongst the excluded decisions set out in clauses 26-29. The Making Decisions Alliance expressed concern about the range of medical treatment decisions which could be taken under the general authority.<sup>141</sup> The Adults with Incapacity (Scotland) Act 2000 requires a formal procedure whereby a Certificate of Incapacity has to be produced for all medical treatment, except in emergencies. Dr. Lyons, a psychiatrist practising in Scotland, told us however that this system ‘proved very difficult to work for many reasons’ and advised us ‘not to go as far down the certification/ documentation road that Scotland has.’<sup>142</sup>

**129. We recommend that the Bill makes provision for a Regulation making power to enable further specific decisions to be excluded from the general authority and therefore always taken to the Court of Protection. This should include:**

- **those decisions currently requiring court authorisation such as requests for the sterilisation of people lacking the capacity to consent;**
- **the withdrawal of artificial nutrition and hydration from patients in a persistent vegetative state;**
- **any procedure of an experimental kind that might carry significant benefits but which also carries significant risks (a situation exemplified by recent attempts to treat a person with new variant CJD); and,**
- **significant decisions concerning the management of an incapacitated person’s financial affairs.**

### ***Dispute resolution mechanisms***

130. As many witnesses pointed out, there is considerable scope for disagreement between relevant parties over what actions might be in the best interests of a particular individual.<sup>143</sup> The draft Bill does not make provision for any form of dispute resolution mechanism save

<sup>139</sup> Ev 284 MIB 1221

<sup>140</sup> See Chapter 16 of this Report and also Ev 43 para 56.12

<sup>141</sup> Q181 (Mr Broach)

<sup>142</sup> Ev 11 MIB 989

<sup>143</sup> Q41 (Mr. McClements), Q281 (Dr. Wilks)

recourse to the Court of Protection. It is clearly not desirable or feasible for all disagreements arising under the draft Bill to be resolved in this way.<sup>144</sup> **We recommend that a right to a second opinion in cases of disagreement which have not been resolved through discussion be included on the face of the draft Bill.**

131. The Law Society recommended the involvement of mediation services in cases where resolution through a court would not be a proportionate response.<sup>145</sup> **We accept the value of mediation services and would like to see reference in the Codes of Practice accompanying the draft Bill to their utility as an alternative mechanism of dispute resolution. In situations where strong disagreements remain over what is in a person's best interests, the dispute should always be referred to the Court of Protection.**

### ***Use of force***

132. The general authority does not authorise the use of force to secure the doing of an act resisted by the person concerned or to restrict that person's movement except to avert a substantial risk of serious harm. It is unclear what is meant by force and what solution should be used if, for example, a person is confused and lacks an understanding of what is happening and refuses to go to hospital for an investigation the purpose of which is to identify the reasons for confusion. Where force or restriction of the person's movement is permitted, the Bill contains no requirement for the risk of serious harm to be immediate, which would justify emergency action being taken. The Law Society contends that such powers, unless more heavily qualified, may amount to 'detention' of the incapacitated person in contravention of the Human Rights Act.<sup>146</sup> Witnesses agreed that there could be circumstances in which the general authority could be used as a defence in court for what many people would regard as an inappropriate use of restraint.<sup>147</sup> **We recommend that clause 7 be redrafted to specify that detention can only be justified in a situation of urgency (including an emergency) and that the period of detention should be as short and least restrictive as possible.**

133. We welcome Lord Filkin's acknowledgement that the Department needs to look again at the way in which the general authority is set out in the draft Bill.<sup>148</sup> Unlike the Adults with Incapacity (Scotland) Act 2000 the general authority ensures that all decisions relating to personal care and health matters are brought within a statutory framework. Despite our concerns, we are convinced that with greater clarification of the intention and scope and with wider and more rigorous safeguards, the general authority would significantly improve the legislative framework for substituted decision making in England and Wales.

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<sup>144</sup> Q314 (Dr. Ehlert)

<sup>145</sup> Ev 224 MIB 1215 paragraphs 8-13

<sup>146</sup> Ev 223 MIB 1212

<sup>147</sup> Q315 (Dr Zigmond)

<sup>148</sup> Q720 (Lord Filkin)



## 9 Chapter 9: (Clauses 8-13) Lasting Powers of Attorney

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134. In 1995, the Law Commission stated that its main policy aim was:

“...to encourage people to take for themselves those decisions which they are able to take. This should cover “anticipatory” decision-making by people who, knowing or fearing that their decision-making faculties may fail, wish to make plans for what is to happen at that time.”<sup>149</sup>

135. Currently, the Enduring Powers of Attorney Act 1985 enables an individual (the donor) to appoint an attorney to take decisions concerning the management of the donor’s property and financial affairs. Under the provisions of the draft Bill, a new system of Lasting Powers of Attorney (LPAs) will allow individuals, whilst competent, to appoint a donee (or donees) to take decisions should the donor lose capacity in the future. The areas of decision-making are extended to include the donor’s personal welfare (including healthcare), in addition to property and affairs. Clause 8(1) of the draft Bill provides that certain procedural requirements must be fulfilled in order to constitute a valid LPA, which then has the effect of conferring authority on the donee to make the types of decisions specified in the LPA when the donor no longer has capacity to make those decisions himself.

136. When the donor has capacity, even temporarily, decision-making authority remains with the donor. However, except for healthcare decisions, an LPA can operate as an ordinary power of attorney, in certain circumstances, when the donor has full mental capacity. An LPA will continue to operate after the donor has lost capacity when the donee will have the full decision-making powers set out in the LPA document.

137. The majority of evidence received by the Committee generally welcomed the inclusion of LPAs in the draft Bill:

“One of the major attractions of a Lasting Power of Attorney (LPA) is that it involves the Donor, whilst he or she has capacity, in nominating the person they would wish to make decisions about personal welfare and property and financial affairs.”<sup>150</sup>

138. The oral evidence sessions, in particular, revealed dissatisfaction with the present system of Enduring Powers of Attorney (EPA). We were very concerned by evidence presented to the Committee indicating that financial abuse occurs in approximately 10-15% of cases involving EPAs.<sup>151</sup> Further evidence estimated that abuse was as high as 20%.<sup>152</sup> A precise figure for the amount of financial abuse is, however, difficult to calculate as it is unclear exactly how many EPAs are in existence since they must only be registered

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<sup>149</sup> Law Commission Report No 231 para 7.1

<sup>150</sup> Ev 30 MIB 950 para 4.6

<sup>151</sup> Q505 (Mr Lush)

<sup>152</sup> Ev 203 MIB 1030 para 3.1

at the point at which the donor is, or is becoming, mentally incapable of managing his own affairs. Some concern was expressed that unregistered EPAs were being used to take advantage of donors who were beginning to lose capacity or were continuing to be used even after the donor had lost capacity. Denzil Lush, the Master of the Court of Protection stated in his submission:

“I don’t believe that, when it published its report on Mental Incapacity in 1995, the Law Commission was fully aware of the extent of financial exploitation, particularly affecting the elderly mentally infirm. Certainly, the more important surveys on abuse have post-dated that report. But, even if it was aware, it failed to address the problem by providing adequate, private law safeguards.”<sup>153</sup>

139. The draft Bill attempts to remedy the situation by requiring an LPA to be executed and registered before it can be used,<sup>154</sup> thereby reducing the difficulties associated with the monitoring of EPAs.<sup>155</sup>

140. The main differences between EPAs and LPAs are:

- LPAs will be able to apply to welfare (including healthcare) matters as well as finances;
- different attorneys can be appointed to make different types of decisions;
- an LPA must include a certificate signed by someone whose qualifications will be set out in Regulations confirming the capacity of the donor to make the power;
- an LPA must be registered with the Public Guardian before it can be used;
- the Public Guardian must notify the donor, donees and other people named by the donor, of an application to register the power; and
- an LPA can appoint a replacement attorney if the donee originally appointed is unable to act for specified reasons.

141. Although LPAs were seen as an improvement on the present system of EPAs, the evidence received by the Committee revealed a recurring theme that clarification of the extent of the powers and further safeguards were required in the draft Bill. The Making Decisions Alliance (MDA) stressed that a greater understanding of the powers under LPA arrangements were needed to emphasise that they were only effective at such times as they were active, namely when the donor lacked capacity. At other times, the donor would be in control of decisions in those areas of life otherwise covered by the relevant LPA, unless the donor had chosen to delegate those decisions to his donee.

142. The draft Bill makes it clear that an LPA relating to personal welfare decisions confers authority on the donee to give or refuse consent to medical treatment,<sup>156</sup> but only when the

<sup>153</sup> Ev 183 MIB 1049 para 4

<sup>154</sup> Clause 8(2)(b)

<sup>155</sup> Q753 (Lord Filkin)

donor lacks capacity to consent for himself.<sup>157</sup> In addition, decisions concerning the refusal of or consent to life-sustaining treatment can only be taken by a donee when the donor lacks capacity and where an LPA contains an express provision that the donee is authorised to make those decisions.<sup>158</sup> The MDA have, however, stated that further clarification is needed in relation to other personal welfare decisions<sup>159</sup> (for example, decisions about where to live) since, by clause 8 of the draft Bill, an LPA can also act as ordinary power of attorney in relation to matters concerning both personal welfare and property and affairs.

143. If a personal welfare LPA is only to be effective when the donor lacks capacity, then it is essential that a donee does not take such decisions when there is capacity, unless delegated to do so. The conditions for decision-making will be particularly important for those who suffer from fluctuating capacity. Donees will be required to make decisions in the best interests of the donor, which will include a requirement to permit and encourage the donor to participate as fully as possible in the process, and to have regard to the donor's past and present wishes and feelings.<sup>160</sup> It will nevertheless be essential that adequate guidance and training are in place, especially for donees of LPAs, in order that they are able to make the distinction; and for health and social care professionals to understand that the creation of a personal welfare LPA does not necessarily confer permanent decision-making authority on a donee.<sup>161</sup>

**144. We recommend that the Bill should make clear whether it is intended that personal welfare decisions, excluding those relating to medical treatment, may be taken when a donor retains capacity. Further, clarification of the extent and limitation of the powers, as well as adequate guidance and training for donees, are also strongly recommended.**

145. The need for further safeguards was also highlighted by a number of witnesses.<sup>162</sup> Particularly, in relation to financial affairs, the Committee were warned that unless further safeguards were included in the draft Bill, individuals would be reluctant to create an LPA.<sup>163</sup>

146. By clause 9(2), the draft Bill limits who can be appointed as a donee for property and affairs by excluding bankrupts. The Committee considered whether excluding other groups would provide additional safeguards. However, the evidence we received did not support this option:

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<sup>156</sup> Clause 10(3)

<sup>157</sup> Clause 10(4)(a)

<sup>158</sup> Clause 10(4)(b)

<sup>159</sup> Ev 30 MIB 950, para 4.6.6

<sup>160</sup> Clauses 4(2)(b) & (c)

<sup>161</sup> Ibid, para 4.6.13

<sup>162</sup> Ev 183 para 8, Ev 219 Q620

<sup>163</sup> Q540 (Professor Williams)



“...we want more emphasis on reviewing and checks and balances and safeguards rather than *carte blanche* excluding groups of people because I think what we do want is people to be able to choose who they want as their LPA.”<sup>164</sup>

147. Several witnesses, although supporting the right of the individual to choose their own donee, agreed that there was a potential for conflict in some cases if the same donee was responsible for both financial and welfare matters, particularly if they had a vested interest in both areas.

“I think we are in a situation where the patient needs to have health warnings similar to those on the existing enduring powers of attorney to highlight the potential conflict and if they make the decision that they want to appoint a spouse, a partner, a child or somebody in whom they have an enormous amount of trust to be the person to make the decision and they are satisfied in their own mind that when they are able to make that decision the individual will not exploit the situation to their own ends, then that is the free choice that they will make at that stage.”<sup>165</sup>

“We would be very inclined to advise donors that it would be essential to think very carefully if they want a lasting power of attorney to have both a financial and a welfare voice on their behalf or appointing two people for the separate roles.”<sup>166</sup>

“... there do need to be regular checks on how that [the LPA] is working and that is very much a court of protection/public guardian office role.”<sup>167</sup>

148. The British Psychological Society commented:

“Basically some sort of mechanism to ensure further safeguards potentially needs to be incorporated in a Codes of Practice.”<sup>168</sup>

149. The Health Minister, Ms. Rosie Winterton acknowledged the need, in some cases, to appoint different donees in relation to different affairs:

“From the health care side it may be that people might want different attorneys for different decisions. Somebody that you trust with your finances may not be the same as somebody that you wanted to make decisions about your health and welfare.”<sup>169</sup>

**150. Whilst we support the intention of the draft Bill to allow individuals the freedom to choose their donee(s) when making an LPA, we recommend that further guidance is provided to warn donors of the potential for conflict. Furthermore, we recommend the inclusion, in Codes of Practice, of an additional safeguard mechanism by which the Court of Protection or the Public Guardian could monitor the use of LPAs with a view to preventing the abuse and exploitation of a donee's powers.**

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<sup>164</sup> Q125 (Ms Wilmington)

<sup>165</sup> Q620 (Mr Raymond)

<sup>166</sup> Q124 (Mr Goss)

<sup>167</sup> Q125 (Ms Thompson)

<sup>168</sup> Q338 (Dr Ehler)

<sup>169</sup> Q754 (Rosie Winterton MP, Minister for Health)

151. We received a number of submissions which queried whether donees acting under an LPA would be subject to a common law duty of care. The British Psychological Society stated that they would welcome a specific provision in the draft Bill to that effect.<sup>170</sup> The Master of the Court of Protection expressed some concern at this omission:

“If you actually read through that legislation, the only people who are required to act reasonably are those under a general authority. That is the only time the word “reasonably” arises. Theoretically you do not have that with deputies and LPAs. .... So you could have somebody who is appallingly incompetent in terms of providing financial needs and requirements but I am not sure I can get rid of them purely on the best interests test as laid out in the Bill.”<sup>171</sup>

152. The British Psychological Society submitted that the draft Bill:

“... should include specific provisions to ensure that recipients of donee powers are placed under an obligation to fulfil these duties properly and that a mechanism for monitoring donees is established, in order to ensure that individuals who are no longer competent to make decisions, are protected from exploitation, abuse and neglect.”<sup>172</sup>

153. Further witnesses stressed the need for a greater degree of accountability for donees to reduce the potential for abuse.<sup>173</sup> Suggestions put forward to the Committee included the requirement of an audit on the basis of a donor’s annual accounts<sup>174</sup> or the imposition of a greater responsibility on financial institutions to monitor accounts, particularly those of old or vulnerable people.<sup>175</sup>

**154. We strongly recommend that an express duty of care is incorporated into the draft Bill in respect of donees acting under an LPA (and for Court Appointed Deputies). We further consider that a greater degree of accountability is required from those groups in order to limit the potential for abuse of their powers and therefore, we recommend the exploration of effective methods to achieve that end.<sup>176</sup> In particular, we recommend that specific requirements in the form of a standard of conduct should be included in the Codes of Practice, aimed at those exercising formal powers under the draft Bill.<sup>177</sup>**

155. One of the significant differences between EPAs and LPAs, as stated above, will be the requirement that an LPA should be registered when the power is granted as opposed to when the donor loses capacity. This would create a situation where an ordinary power of attorney might be created on registration and when the donor still has capacity. The potential consequences for personal welfare LPAs were mentioned in paragraphs 142-144

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<sup>170</sup> Q336 (Dr Kinderman)

<sup>171</sup> Q51 (Mr Lush)

<sup>172</sup> Ev 120 MIB 1205

<sup>173</sup> Q540 (Professor Williams)

<sup>174</sup> Q338 (Dr Ehler)

<sup>175</sup> Q507 (Mr Lush) referring to recommendations in the Consultation Paper on ‘Law and the Elderly’ issued by the Law Reform Commission of Ireland

<sup>176</sup> See para 87

<sup>177</sup> See 13 chapter on Codes of Practice

above. In relation to financial affairs, a number of groups have expressed concern as to the operational difficulties for financial institutions in determining the point at which the donor is actually incapable and therefore, it is correct to only deal with the donee.<sup>178</sup> Although there is a general presumption of capacity throughout the Bill, it is highly unlikely that financial institutions will have sufficient expertise to determine whether a donor has capacity at any material time. The British Bankers' Association has urged the Committee to leave unaltered the current process for registration of a power of attorney, namely when the donor of the power is, or is becoming, mentally incapable.<sup>179</sup> However, some witnesses commented that the cost might deter individuals from registering LPAs, which they might never need to use because they might not lose capacity:

“....they think they will leave it and they can register it if ever they do need it, so you are back to the old EPA issue about who decides when you lose capacity enough to get it registered.”<sup>180</sup>

156. Under the new system of LPAs, the requirement that a certificate of capacity is required on registration<sup>181</sup>, would, however, prevent registration if the donor had already lost capacity.

157. **We have concluded that the proposed system requiring the registration of LPAs before use will assist in monitoring the use of LPAs and detecting possible abuse. However, we recommend that donees should be placed under an obligation to notify both the donor and the Public Guardian that the donor is, or is becoming incapacitated, thereby putting this information on the public record and opening it up to challenge. We further recommend that guidance should be provided to assist financial institutions to deal with the operational realities of LPAs.**

158. Schedule 1 of the draft Bill contains the requirements for executing LPA instruments. The donor of an LPA must state, *inter alia*, the names of a person or persons he wishes to be notified of any application to register the instrument<sup>182</sup>, or that there are no such persons.<sup>183</sup> The Law Society have expressed concern that ‘extreme caution should be taken where there are no named persons for notification’ as it could be an indication that the LPA was not made or registered with the donor’s own free will.<sup>184</sup> Although there is a requirement that, on registration, an LPA must be accompanied by a certificate from a prescribed person as to the capacity of the donor,<sup>185</sup> that safeguard would not necessarily preclude the presence of duress. Accordingly, the Law Society have recommended that:

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<sup>178</sup> For example, Ev 30 MIB 950 Ev 464 MIB 1220

<sup>179</sup> Ev MIB 1220

<sup>180</sup> Q126 (Ms Thompson)

<sup>181</sup> Schedule 1, para 2(e)

<sup>182</sup> Schedule 1, para 2(1)(c)(i)

<sup>183</sup> *Ibid*, para 2(1)(c)(ii)

<sup>184</sup> Ev 203 MIB 1030 para 4.3

<sup>185</sup> Schedule 1, para 2(e)



“An application for registration without persons named for notification should be witnessed in the presence of the person who certifies capacity and two other persons.”<sup>186</sup>

159. We believe that the additional safeguard of requiring two additional persons to witness the certification of capacity should be included where there are no named persons for notification of the registration of an LPA.

## 10 Chapter 10: (Clauses 14-22) The Court of Protection and Court Appointed Deputies

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160. Clauses 14 – 22 make provision for the new Court of Protection to make substitute decisions about both financial and welfare matters for an incapacitated person who has not previously made an LPA, or to appoint a ‘deputy’ to do so. Details of the new Court of Protection, its powers and procedures, are set out in Part 2 of the draft Bill. The proposals for court appointed deputies will replace the current system of receiverships and extend powers to include welfare and healthcare matters as well as financial and property affairs.

161. The proposals for the new Court of Protection were recommended by the Law Commission in 1995:

“This jurisdiction will have a number of new distinctive features. It will provide a single integrated framework for the making of personal welfare decisions, health care decisions and financial decisions. It will provide for both “one-off” orders or, where necessary, for the appointment of a “manager” with continuing powers.”<sup>187</sup>

162. In ‘Making Decisions’ the Government accepted the Law Commission’s recommendation and commented:

“Most respondents favoured a single court jurisdiction for all areas of decision-making. Although there were some concerns about the Court of Protection’s perceived lack of accessibility and unsuitability for dealing with emergencies, no realistic alternatives were proposed, and a clear majority of respondents supported the Court of Protection exercising this jurisdiction.”<sup>188</sup>

163. The Court will have the power to make declarations as to an individual’s capacity, as to whether a particular act or omission taken in relation to the individual is lawful and to give directions to deputies. In cases where there is no need for on-going decision making powers, the Court will be able to make a single order enabling a particular matter to be resolved. Such orders can include straightforward decisions (such as the sale of property)

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<sup>186</sup> Ev 203 MIB 1030 para 4.3

<sup>187</sup> Law Commission Report No 231, para 8.1

<sup>188</sup> October 1999, Cm 4465, para 3.4

as well as major or difficult decisions (including some medical treatment decisions) or resolving disputes where people cannot agree (e.g., where an incapacitated person should live or who he/she should have contact with). In deciding whether to grant permission for an application to be made for court intervention, the Court has to be satisfied that a court order or directions will benefit the person lacking capacity and it is not possible to resolve the matter without going to Court.<sup>189</sup> Clause 16(3) of the draft Bill provides that the powers of the Court to make decisions and to appoint deputies will be subject to the best interest checklist in clause 4.

164. The Committee is concerned that the draft Bill fails to give adequate guidance to the Court to determine when it will be in an individual's best interests to appoint a deputy. **We recommend that further guidance should be provided to assist the Court of Protection in deciding when a single order is more appropriate than the appointment of a deputy.**

165. It is intended that that the Court will have a regional presence and be able to sit at any place in England and Wales.<sup>190</sup> In connection with its jurisdiction, it will have the same 'powers, rights, privileges and authority as the High Court.'<sup>191</sup> Furthermore, certain groups will not require permission to apply to the court.<sup>192</sup> In particular, no permission is required for an incapacitated person or someone acting on their behalf.

166. The proposals for the new Court generated a similar response to that presented by the Government in 'Making Decisions'. The principle of a unified Court of Protection with the powers and a regional presence provided by the draft Bill were strongly welcomed by our witnesses.<sup>193</sup> However, there was widespread concern as to whether the Court would be accessible to carers and persons lacking capacity<sup>194</sup> and how single orders of the Court would be enforced and by whom.

167. Article 6 of the European Convention on Human Rights<sup>195</sup> requires access to a fair and impartial judicial hearing for the determination of civil rights and obligations. Lord Filkin, the Parliamentary Under-Secretary for State for the Department submitted that it would be:

"easier to go to the Court of Protection than it is to go to the High Court."<sup>196</sup>

168. Although resort to the Court is intended to occur only when a benefit to the person lacking capacity cannot be achieved in any other way,<sup>197</sup> a number of witnesses strongly criticised the draft Bill for failing to provide a suitable alternative to the Court, or assistance

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<sup>189</sup> Clause 40(3)(c)&(d)

<sup>190</sup> Clause 34(2)

<sup>191</sup> Clause 37

<sup>192</sup> Clause 40

<sup>193</sup> Ev 30 MIB 950 para 4.9

<sup>194</sup> Ev 30 MIB 950 para 4.9.1; Ev 203 MIB 1030 para 8.1

<sup>195</sup> As set out in Schedule 1 of the Human Rights Act 1998

<sup>196</sup> Q715

<sup>197</sup> Clause 40(3)(d)

for people with capacity problems to be able to take up their concerns, such as independent advocacy.<sup>198 199</sup>

People First submitted:

“The draft bill does not give people who are having choices made for them a right to an independent advocate. If the government were really serious about making sure people who find it hard to make choices were in control of their lives, they would be making a law giving us a right to independent advocacy.”<sup>200</sup>

169. This view was supported by the Law Society, who pointed out the difficulties faced by people lacking capacity in obtaining legal advice and pursue a case in court.<sup>201</sup> They saw a “fundamental role” for advocates in helping incapacitated people to gain access to justice, not least by helping them to instruct lawyers if there is no other way of resolving a dispute than taking it to court.

170. On the basis of the evidence, the Committee are of the opinion that the same criticisms that were set out in ‘Making Decisions’ four years ago are still relevant to the draft Bill, namely ‘a perceived lack of accessibility and unsuitability for dealing with emergencies.’<sup>202</sup> We are of the opinion that access to the new Court of Protection could be further enhanced for persons lacking capacity. **We strongly recommend that further consideration is given to the provision of independent advocacy services and other means of enabling people lacking capacity to participate as fully as possible in any hearing affecting their rights and entitlements.**

171. The issue of court costs was also seen as an essential factor in determining whether the Court would be accessible:

“The MDA welcomes the provision for the Court to make single orders on important decisions. However, the MDA would be concerned if the costs of such orders were so high that it would act as a disincentive.”<sup>203</sup>

172. In a paper provided by the Department for Constitutional Affairs on Implementing the draft Bill, we were told that there will be provision for “specialist but limited public funded legal advice where this is necessary for cases of particular seriousness and complexity”.<sup>204</sup> Yet other witnesses expressed the view that:

“The objectives of this Bill will be wholly undermined without adequate public funding”<sup>205</sup>

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<sup>198</sup> Ev 228 MIB 778; Ev 30 MIB 950

<sup>199</sup> See Chapter 16

<sup>200</sup> Ev 228 MIB 778

<sup>201</sup> Q634 (Mr Clements)

<sup>202</sup> ‘Making Decisions’ (CM 4465) Chapter 3, para 3.4

<sup>203</sup> Ev 30 MIB 950 para 4.9

<sup>204</sup> Enclosure to letter dated 31 October 2003 from Lord Filkin to Lord Carter, MIB 1222

<sup>205</sup> Ev 203 MIB 1030



173. We seek assurances that public funds will be made available to ensure that the Court of Protection is sufficiently accessible for those with limited assets. Furthermore, we seek clarification as to the types of cases for which legal aid will be provided to mentally incapacitated applicants and alternative remedies for those cases which will not qualify.

174. Clause 19 of the draft Bill provides for the appointment and powers of court appointed deputies. Restrictions on those powers are set out on clause 20. Like LPAs a deputy's powers will include making decisions on personal welfare as well as property and affairs. The Court will be able to appoint more than one deputy to act on behalf of an individual who lacks capacity and the deputies can act jointly or jointly and severally. In deciding whether the appointment of a deputy or deputies is in the best interests of an individual, the Court must first consider whether a single order will be preferable to the appointment and, secondly, if a deputy is to be appointed, the appointment should be as limited in scope and duration as possible.

175. Our inquiry revealed a general consensus that the deputy system was seen as a desirable feature of the draft Bill:

“We acknowledge the need for this set-up should the person be born with impaired capacity, or lose their capacity without having made previous arrangements to nominate an LPA”<sup>206</sup>

176. Although some witnesses believed that the draft Bill provided sufficient checks and balances on the powers of court appointed deputies,<sup>207</sup> others disagreed:

“...there need to be full checks and balances to ensure that decisions made by Deputies on behalf of people who lack capacity are in their best interests. Whilst we welcome the restrictions on Deputies set out in clause 20, we feel that they do not go far enough in safeguarding the rights of people who lack the capacity.”<sup>208</sup>

177. In common with evidence received on LPAs,<sup>209</sup> the additional safeguards that were proposed to the Committee included a standard of care to be imposed on deputies.<sup>210</sup> Although there is a duty on the Lord Chancellor to prepare Codes of Practice for the guidance of deputies<sup>211</sup> the Law Society further submitted:

“...that a checklist would be of some assistance in maintaining a standard for court appointed deputies.”<sup>212</sup>

<sup>206</sup> Ev 30 MIB 950, para 4.7.1

<sup>207</sup> Q204 (Mr Broach)

<sup>208</sup> Ev 30 MIB 950, para 4.7.1

<sup>209</sup> See Chapter 9

<sup>210</sup> For example, Q511 (Mr Lush)

<sup>211</sup> Clause 30(1)(d)

<sup>212</sup> Ev 224 MIB 1215

178. The MDA stated that the Court of Protection needed to be given powers to make checks about the competency or capacity of the applicant to carry out their functions as a deputy and to investigate conflicts of interest.<sup>213</sup>

“For example, if a care home manager was already the deputy for five of his residents and a sixth application was made, we would want the court of protection to investigate whether that was appropriate.”

179. A further area where the Committee foresaw a potential for conflict was in cases where a social worker was appointed as a deputy. As an employee of a local authority, a social worker would owe a duty to his employer, but circumstances might well arise where that duty would conflict with his role as a deputy requiring him to act in the best interests of an incapacitated person. The Association of Directors of Social Services conceded:

“It is better in many instances for us to come in in an investigatory capacity rather than to have it on a long-term basis.”<sup>214</sup>

**180. We believe that further guidance is required for deputies as to the standard of conduct they must maintain in the operation of their duties.**

181. Moreover, to minimise the potential for conflicts of interests, we urge that guidance should be issued to the Court of Protection to assist in the appointment of the most appropriate individual to act as a deputy.

182. A number of witnesses were also dismayed that by clause 17(d) of the draft Bill, deputies’ powers would extend to refusing consent to the carrying out or continuation of medical treatment.<sup>215</sup> The Foundation for People with Learning Disabilities submitted:

“...if deputies can make a decision regarding withdrawal of treatment, the decisions need to go to court and be very, very seriously considered. I think the withdrawal of nutrition and hydration is a very painful experience and that, if people choose to in their advance directive, that is one thing, but to assume that for someone who does not have the capacity undermines their right to life.”<sup>216</sup>

183. Under the mechanisms of LPAs and advance decisions, the refusal of consent to the carrying out or continuation of treatment can only be given if authorised by the individual when he was capable. However, under the structure of court appointed deputies, the withdrawal of treatment could be consented to even though the appointment would not have been made by the individual patient. The Catholic Union submitted:

“...it is highly likely that such an appointee will be some official such as the chief Social Worker for the area concerned. Thus the chief Social Worker for the area is likely to be making decisions about the provision of treatment (or even sustenance

<sup>213</sup> Ev 30 MIB 950 para 4.7.3

<sup>214</sup> Q480 (Mr Dixon)

<sup>215</sup> See for example Ev 30 MIB 950, Ev 419 MIB 1193

<sup>216</sup> Q237 (Ms Morgan)

by tube) to the patient and thus perhaps making a decision about whether that patient should continue to live or not, even though that social worker is not medically qualified and has no medical duty of care. That is clearly a matter for considerable concern.”<sup>217</sup>

**184. We strongly urge that the provisions allowing deputies to consent to treatment be restricted to exclude the withdrawal or refusal of life-sustaining treatment. Unless there is a valid LPA or advance decision expressing the individual’s wishes in relation to the subject, decisions relating to the carrying out or continuation of life-sustaining treatment should be referred to the Court of Protection for determination.**

185. Evidence was submitted to the Committee that there was some confusion as to whether certain decisions should be taken, or acts done, under the general authority or by the appointment of a deputy. The MDA expressed concern that the borderline between the general authority, and the occasion when an application should be made for the appointment of a deputy, was unclear:

“...with the general authority being so broad, we do not really see many situations where a family or carer would feel the need to apply to become a deputy. That is a problem which is again a reason why the general authority needs to be more circumscribed.”<sup>218</sup>

186. Accordingly it is foreseeable that, due to the wide scope of the general authority, decisions will be taken or acts done under the general authority even though they might be more appropriate for a deputy to undertake. A deputy will only be appointed if the court is satisfied that the appointment is in a person’s best interests and the powers conferred on the deputy will be as limited in scope and duration as possible.<sup>219</sup> The appointment will therefore provide safeguards lacking in the exercise of the general authority.

**187. The Committee strongly recommend that it should be made clear on the face of the Bill which decisions or acts should fall under the remit of a court appointed deputy and not under the general authority. Furthermore, guidance should be provided to family members, carers and others exercising the general authority as to the point at which it would be appropriate to apply to the Court of Protection for the appointment of a deputy.**

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<sup>217</sup> MIB 1193, para 38

<sup>218</sup> Q205 (Mr Broach)

<sup>219</sup> Clause 16(4)



## 11 Chapter 11: (Clauses 22-26) Advance Decisions to Refuse Treatment

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188. Clauses 23 to 25 of the draft Bill set out the circumstances in which persons with capacity, having reached the age of 18, may express in advance a decision about what treatment they would wish not to have if they were subsequently to become incapable.

189. Clause 23 (1) defines such a decision as being intended:

“so that if -

- a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him; and
- b) at that time he lacks capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.”

190. Clause 23 (2) provides that the ‘treatment’ concerned in such a decision can be expressed in broad terms and in non-scientific language. According to Clause 23 (3) the decision can be withdrawn or altered at any time providing that the person making it has the capacity to do so.

191. Clause 24 defines the lawfulness of such a decision. The key points are that to be valid the person making it must have been capable at the time it was made and that it should be applicable to the treatment concerned. It would not be valid if the person making it had subsequently withdrawn it, whilst capable of doing so, or had subsequently conferred authority under a Lasting Power of Attorney to a donee to give or refuse consent to that treatment. Nor would it be valid if the person making it had

“done anything else clearly inconsistent with the advance decision remaining his fixed decision”.

192. If they still had capacity, any wish expressed at the time of treatment would over-ride any previous advance decision.

193. In Clause 24 (4) the draft Bill makes clear that any advance decision would not be valid if the treatment proposed was not what was specified in the advance decision or if the circumstances specified were absent. Nor would it be valid in circumstances which could not have been anticipated by the person at the time of making the advance decision and which would have affected that decision had they anticipated them. Most importantly, it makes clear that advance decisions are only applicable to life-sustaining treatments where they are specified in the decision.

194. Clause 25 sets out the effects of such advance decisions. It states that a valid advance decision has the same effect as a statement refusing treatment made by a person who is

capable at the time of making it. This would give statutory confirmation to existing court rulings<sup>220</sup> that a treating doctor is obliged to respect a lawfully-made advance decision about a specified treatment. It follows that it would be unlawful for a treating doctor to knowingly ignore such a decision.

195. A very considerable number of written submissions were received expressing grave concern about this aspect of the draft Bill.<sup>221</sup> Many argued from a standpoint of moral conviction that it was wrong to introduce a statute that could enable decisions that would effectively shorten life.<sup>222</sup> Others argued that it was wrong to require a doctor not to give treatment that the doctor believed was in a patient's best clinical interests.<sup>223</sup>

196. A considerable body of written evidence claimed that the inclusion of advance decisions meant that the Bill was introducing 'euthanasia by the backdoor'.<sup>224</sup> We took evidence on this matter and considered the issues at length. For several faith organisations and the Guild of Catholic Doctors<sup>225</sup> the omission of treatment that might prolong life even if for a short period of time was considered unacceptable unless such treatment was likely in itself to result in undue suffering.<sup>226</sup> We noted that there was nothing in the Bill that allowed for an act that had the clear intent to end a person's life. This was confirmed in oral evidence by the Parliamentary Under-Secretary of the Department for Constitutional Affairs, Lord Filkin.<sup>227</sup>

197. Allied to these concerns, numerous witnesses objected to the fact that the draft Bill allows life-sustaining treatment (e.g. artificial ventilation) to be refused.<sup>228</sup> They drew attention to the Court ruling in the case of *Bland*<sup>229</sup> that the provision of hydration and nutrition by artificial means amounted to 'treatment'.<sup>230</sup> They argued that withdrawal of nutrition and hydration would result in undue suffering and an unpleasant and undignified death.<sup>231</sup> The BMA in their evidence suggested that, while the use of artificial means of nutrition and hydration amounted to treatment and could therefore be refused, the Bill should stipulate that basic care could not be refused.<sup>232</sup>

198. Witnesses from the medical profession<sup>233</sup> also put it to us that: a) people when capable could not foresee how they might wish to act if they were to become incapable and therefore should not commit themselves to a course of action from which they could not

<sup>220</sup> See, for example, re C (a patient) [1991] 3 All ER 866 and Re T (Adult: Refusal of Treatment) [1993] Fam 95; [1992] 4 All ER 649

<sup>221</sup> See for example Ev 138-140 MIB 781, Ev 143 MIB 1191

<sup>222</sup> See for example Ev 145 MIB 1187 and Ev 140 MIB 679

<sup>223</sup> Ev 135-140 MIB 781, Ev 309 MIB 403

<sup>224</sup> See for example Ev 292 MIB 20, Ev 307 MIB 403

<sup>225</sup> MIB 352 Ev 425, Ev 313 MIB 457, Ev 135 MIB 781, Ev 455 MIB 969 and Ev 133 MIB 1001

<sup>226</sup> Ev 135 MIB 781

<sup>227</sup> Q739 (Lord Filkin)

<sup>228</sup> Ev 308 MIB 110

<sup>229</sup> Airedale NHS Trust v Bland [1993] AC 789

<sup>230</sup> Q421 (Archbishop Smith)

<sup>231</sup> Ev 165 para 7

<sup>232</sup> Ev 96 Q266 (Dr Wilks, Dr Nathanson)

<sup>233</sup> Ev 103 MIB 817 para 7, Ev 104 MIB 824, Ev 162 MIB 1203 para 12 (Ev 141 MIB 183, Ev 135 MIB 781, Ev 487 MIB 1164, Q384 (Dr Gardner), Q387 (Dr Howard) Q414 (Dr Treloar) Q420 (Dr Craig)

withdraw having become incapable; b) unforeseen circumstances, such as the development of a new treatment the use of which would be in their best interests, could arise after the advance decision had been made; and c) the course of action specified in the advance decision might prolong suffering rather than relieving it. We heard evidence from Professor the Baroness Finlay of the difficulties she and her medical and nursing colleagues faced working in palliative care services. She told us that her personal choice would be that Advance Decisions should always be advisory “but case law seems to have taken us beyond that point already”.<sup>234</sup>

199. Those who believed that advance decisions should be included argued<sup>235</sup> that this was a logical and appropriate continuation of respect for a patient’s individual autonomy in matters of medical treatment. The law already recognises that a capable person can refuse treatment even if that refusal might end their life. But for a doctor to proceed with treatment under such circumstances would be unlawful. Thus it was argued that the draft Bill only proposed to regularise the existing status quo and that it was a logical extension of the established principle of autonomy.<sup>236</sup> For these reasons the Making Decisions Alliance, for example, strongly supported the inclusion of advance decisions to refuse treatment in the Bill.<sup>237</sup>

200. Several witnesses regretted that the draft Bill did not require advance decisions to be made in writing, witnessed or made with the benefit of professional advice.<sup>238</sup> Others feared that people might make advance decisions while in a state of despair or depression that they would not have made under more normal circumstances.<sup>239</sup> The risk of advance decisions being made under coercion was also raised.<sup>240</sup>

201. We have considered the proposal put forward by several witnesses<sup>241</sup> that the specific provisions relating to advance refusals of medical treatment should be excluded from the Bill. This would leave in place the common law provisions which have made valid and applicable refusals effective. But this would create undesirable uncertainty over how advance decisions might fit into the Bill’s proposed statutory decision-making hierarchy. In particular, the proposed powers of donees, deputies and the Court to make healthcare decisions would have no common law equivalent.

202. Moreover, if the Bill contains no mention of advance decisions to refuse treatment, the Court of Protection cannot be given a statutory power to decide whether an advance decision has been validly made, including any question of the person’s capacity to make it or whether it is applicable in particular circumstances. That would mean that the High Court would continue to resort to its inherent jurisdiction in relation to adults who lack capacity (a jurisdiction which will otherwise have become largely redundant) to resolve

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<sup>234</sup> Q362 (Professor the Baroness Finlay of Llandaff)

<sup>235</sup> Ev 39 MIB 950 para 4.8

<sup>236</sup> Ev 333 MIB 742 para 12 (Appendix 36)

<sup>237</sup> Ev 30 MIB 950

<sup>238</sup> Ev 162 MIB 1203 para 9, Ev 166 Q9

<sup>239</sup> Ev 148 MIB 1187

<sup>240</sup> Ev 200-201 MIB 1210

<sup>241</sup> Ev 151 Q387 (Dr Howard)



such matters. In our view, this would leave a very significant and undesirable gap in the Bill's provisions. This would be contrary to the draft Bill's intention, which we support, to create a comprehensive and accessible framework of statutory legislation.

### ***Recommendations***

203. We recommend that the Bill should permit the making of advance decisions to refuse treatment. We recognise the genuine and deeply-felt concern of those who have moral objections to any decision being taken that could end life, but that right is recognised in law for those who are capable of making such decisions and we think it is right that the Bill should provide for those who wish to do so to have the legal means to have that decision respected should they become incapable. In doing so, the Bill should aim to set standards for good practice and ensure a means of challenge under circumstances where there were disagreements that could not be resolved.

204. Many of the fears which have been raised with us about possible connections between the draft Bill and euthanasia appear to be misplaced. Nevertheless, in acknowledgment of the strength of feeling that clearly exists on this issue and in the hope that such misplaced fears do not detract attention from the many worthwhile aspects of the draft Bill, we recommend that additional assurance should be offered by the inclusion of a paragraph in the Statement of Principles we have recommended, or by an additional clause in the Bill, to make clear that nothing in the Bill permits euthanasia or alters the law relating to it.

205. In most circumstances we believe that it would be reasonable for the Bill to require that advance decisions to refuse treatment should be recorded in writing and witnessed by two independent persons having no financial interest in that person's estate. An exception might, however, be made where the decision was taken during ongoing medical treatment in which case it should be recorded by the doctor in charge of the treatment in the patients notes and independently witnessed. We believe that all individuals should be encouraged to register their advance decision with their doctors.

206. We recognise that advance decisions which they may not otherwise wish to make may be made by those suffering from depression, stress or other conditions that would affect their judgment. We also fully appreciate the potential for coercion or other malevolent actions on the part of others to secure advance decisions from vulnerable people. We therefore recommend that the Codes of Practice should require doctors to satisfy themselves that any advance refusal of treatment is valid and applicable.

207. We also recommend that the Department should issue sensitive public guidance designed to promote better understanding of what is involved in making advance decisions. This should explicitly state that any advance decision to refuse treatment should be made voluntarily. It should also include encouragement to seek appropriate professional advice before making such decisions, aimed at ensuring that they were made in the full knowledge and understanding of any relevant medical factors and written in an appropriate form. The Departmental guidance might include a suitable

specimen pro-forma. It should also encourage them to update such decisions regularly, especially in the light of relevant medical developments.

208. We also recommend that the Codes of Practice should set out what should be considered by any doctor, when treating a person who is incapacitated and who is known to have made an advance decision, in determining whether such an advance decision is valid and appropriate. The Code should also state that, under these circumstances, any reasons why such an advance decision was considered valid, invalid or inappropriate must be recorded in that person's health records.

209. We believe that clause 24(4) in the draft Bill is sufficient to address the specific concern about new and unanticipated treatments becoming available which might have a bearing on an advanced decision. We recommend that specific guidance on this be given in the Codes of Practice.

210. We believe that people, whether incapable or not, have the right to expect that they will be cared for to the highest standards. We recommend that the Codes of Practice should explicitly state that the duties and responsibilities placed on health professionals must apply equally to capable and incapacitated people. No assumption should be made that life has less value for the latter.

211. We recommend that the Bill should seek to draw a distinction between basic care (which would include the giving of nutrition and hydration by normal means as well as actions to assist general hygiene and comfort), and the use of artificial means of nutrition and hydration, such as drips or naso-gastric tubes. We support the view that the former falls outside what is normally considered to be treatment and should always be available to people whereas the latter should be regarded as treatment in that the decision to use such artificial means is a clinical one to be made in accordance with best professional practice, and in the best interests of the patient concerned, and having consulted those specified in Clause 4 (2)(d).

212. We further recommend that the use of such artificial means should be determined by the doctors concerned in consultation where possible with the patient's family, friends or recognised representatives, on the basis of that patient's best interests and having due regard to previously expressed wishes given in any advance decision. If a valid and clearly expressed wish not to have artificial means of nutrition and hydration is expressed, and the advance decision is otherwise valid, then that wish should be respected.

## 12 Chapter 12: (Clause 27) Linkage with the Mental Health Act/Bill

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### Clause 27: Interface with mental health legislation

213. It has been pointed out to us that, in relation to the provision of healthcare and treatment for mental disorder, there is potential for a significant overlap between the draft Mental Incapacity Bill (MI) and mental health legislation (MH), either the existing Mental Health Act 1983 or any future Bill to reform mental health law.<sup>242</sup> Both provide substitute decision-making structures for a similar, but not identical, population yet there are significant differences in approach between them. In particular, Professor Genevra Richardson stressed that “the position of people who could potentially be covered by either [statute] needs extensive clarification”.<sup>243</sup>

214. The purpose of the draft Bill is to provide a comprehensive statutory framework for decision-making on behalf of adults who lack capacity to make their own decisions because of mental disability. However, mental health legislation, as it is envisaged at present, has a more specific purpose - to provide a legal framework covering the use of compulsory powers to require people with mental disorder to comply with medical treatment for their disorder without their consent. It is a requirement of the European Convention on Human Rights (Article 5) that any deprivation of liberty, including detention or compulsory treatment of “persons of unsound mind”, must be in accordance with a procedure prescribed by domestic law. Under the current law, the Mental Health Act 1983 sets out the required procedure, although this may be replaced by a new MHA in the not-too-distant future.

215. In her submission to us, Professor Richardson helpfully summarised the main differences in approach as follows:<sup>244</sup>

- Capacity: MI Bill applies only to those who lack capacity: MH does not require an absence of capacity
- Best interests: MI requires decisions to be made in [the incapacitated person’s] best interests: MH has no such requirement
- Medical treatment: MI deals with medical treatment for all conditions: MH covers only treatment for mental disorder
- Resistance: MI allows care and treatment despite resistance in certain circumstances only: MH is specifically designed for cases of active non-compliance
- Safeguards: MH contains more automatic safeguards for the patient

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<sup>242</sup> See for example Ev 372 MIB 556, Ev 104 MIB 824, Ev 203 MIB 1030, Ev 85 MIB 1188

<sup>243</sup> Ev 372 MIB 556 para 12

<sup>244</sup> Ev 372 MIB 556 para 4



- Advance decisions: MI codifies the common law rules on advance decisions to refuse treatment: MH makes no mention of advance decisions.

216. A number of witnesses emphasised the need for priority to be given to introducing mental incapacity legislation first and then reviewing the exact place of mental health legislation in the light of experience following the passing into law of any Mental Incapacity Act.<sup>245</sup> In particular, the Royal College of Psychiatrists expressed the view that, once a comprehensive Mental Incapacity Act is in place, there may be no need for a Mental Health Act other than to deal with people with mental disorder who may pose a danger to others.<sup>246</sup> Our task in considering the interface between both pieces of legislation has been made more difficult by a number of uncertainties, not only concerning the timing of law reform, but also whether our recommendations should relate to the Mental Health Act 1983 and/or the draft Mental Health Bill issued for consultation in 2002<sup>247</sup> or to future proposals for reform of mental health law to be introduced after this Bill.

**217. We recommend that priority should be given to introducing the Mental Incapacity Bill so that account can be taken of these provisions in framing new mental health legislation.**

218. Where incapacitated adults require treatment for mental disorder, they can be treated informally (at present under the common law and in future under the general authority provided by the draft Bill), so long as the treatment is considered to be in their best interests. Alternatively, and in particular for people without capacity who are resisting treatment, the compulsory powers available in the MHA 1983 may be used. We have therefore considered the interface between the Bill and the 1983 Act.

### ***Mental Health Act 1983***

Clause 27 of the draft Bill states that the Bill's decision-making powers cannot be used to give or to consent to treatment for mental disorder if the treatment "is regulated by Part 4 [sic] of the Mental Health Act 1983". The purpose of Part IV of the 1983 Act is to clarify the extent to which treatment for mental disorder can be imposed on detained patients in hospital. We believe the intention of Clause 27 is to ensure that once an incapacitated person has been detained in hospital under the MHA 1983, the powers available under Part IV would 'trump' the decision-making powers under the Bill. However, it has been put to us that an alternative interpretation would be that the MI Bill would not apply in any case in which treatment regulated under Part IV may be required, i.e. when the MHA could *potentially* be applied.<sup>248</sup> The effect of this would be to require the compulsory detention under the MHA of any person lacking capacity to consent to treatment for mental disorder, regardless of the circumstances. This would seem to be both undesirable and impractical.

<sup>245</sup> See for example Ev 85 MIB 1188, Ev 203 MIB 1030, Ev 104 MIB 824

<sup>246</sup> Q297 (Dr Zigmond)

<sup>247</sup> Department of Health, *Draft Mental Health Bill* (2002) Cm 5538 I-III

<sup>248</sup> Ev 372 MIB 556 para 7 Ev 104 MIB 824 para 3.13

219. The Department of Health has since clarified that a narrower interpretation is intended, so that: “Where a person with mental disorder is ... brought under the formal powers of the MHA, it is right that the provisions of the Mental Incapacity Bill are not applied in relation to their treatment for mental disorder”.<sup>249</sup> However, for all other decisions affecting that person, the principles and provisions of the draft MI Bill would apply. **We recommend that the drafting of Clause 27 be amended to clarify its intended purpose.**

220. Since Clause 27 is only intended to apply to patients who are brought under formal powers of the MHA, there would then seem to be a choice of decision-making structure for clinicians who wish to give treatment for mental disorder to people lacking capacity to consent. Guidance issued by the Department of Health indicates that for incapacitated patients who are non-compliant or who resist treatment, an application should be made for compulsory admission to hospital under the MHA in order that treatment for mental disorder can be given.<sup>250</sup> However, it has been pointed out to us that since Clauses 7 and 10 of the draft Bill allow an incapacitated person’s resistance to be overborne in certain circumstances to avert a risk of harm, it may also be possible for treatment to be given under the general authority, or with the consent of a donee of an LPA, even if the person resists.<sup>251</sup> We have already recommended that the drafting of clauses 7 and 10 should be tightened up to restrict their use to urgent situations and for as short a period as possible and not where there is an on-going need for restriction of the person’s liberty (see paragraph 132).

221. The differences in approach of the draft Bill and the MHA carry both advantages and disadvantages. Decisions taken under the draft MI Bill must be in the patient’s best interests, which involves taking account of the patient’s past and present wishes and feelings, consulting with relatives and carers and seeking the least restrictive option. People who have prepared in advance for their incapacity, by making an LPA or an advance decision to refuse treatment, should have their decisions respected (although detention under the MHA would appear to overrule these decisions). On the other hand, detention under the MHA provides an entitlement to certain statutory safeguards which are not available to patients treated informally. These include:

- Application for admission to hospital made by an approved social worker on the basis of two medical recommendations
- Right of appeal to the Mental Health Review Tribunal
- Right to a second opinion for longer-term treatment and for specified forms of treatment (such as electro-convulsive therapy or psychosurgery)
- Right of discharge by the ‘nearest relative’

<sup>249</sup> Letter from Department of Health to the Clerk of the Joint Committee, 6 November 2003

<sup>250</sup> Mental Health Act 1983 Codes of Practice, para 19.27; Health Service Circular 1998/122

<sup>251</sup> Ev 372 MIB 556 para 8 MIB 1110 para 13.3

- Oversight by the Mental Health Act Commission

**222. We recommend that the Codes of Practice include clear guidance to govern the choice of legal powers to provide treatment for mental disorder of people lacking capacity to consent.**

### ***The ‘Bournewood gap’***

223. In considering these differences in approach, we have received conflicting evidence as to whether the provisions of the draft Bill are sufficient to fill the so-called gap in the law identified in the *Bournewood* case.<sup>252</sup> As a result of the House of Lords decision in this case, it appears that it may now be wrong to use the Mental Health Act when admitting an apparently assenting incapacitated person to hospital for the treatment of their mental disorder. In the words of Lord Steyn, “The general effect of the decision of the House of Lords is to leave compliant patients without the safeguards enshrined in the 1983 Act. This is an unfortunate result.”<sup>253</sup> A decision is currently awaited from the European Court of Human Rights in this case as to whether the current law is incompatible with the European Convention.

224. In evidence to the Committee, Health Minister Ms Rosie Winterton confirmed the Government’s view that there was no incompatibility, but indicated that the opportunity of new legislation could be used to build on existing common law safeguards and provide additional protection for compliant incapacitated people.<sup>254</sup> The examples she gave (right to advocacy, appointment of a ‘nominated person’ and access to a tribunal) are those proposed in Part 5 of the draft Mental Health Bill, and not the Mental Incapacity Bill, although she said there was an issue about which Bill should contain the proposed safeguards. Correspondence from the Department has indicated that the awaited judgment of the European Court of Human Rights will inform a reassessment of policy and hence affect the drafting of both Bills.<sup>255</sup>

**225. We request clarification as to whether it is intended to incorporate additional safeguards for compliant incapacitated patients into the draft MI Bill if there is likely to be a delay in implementing the provisions proposed in Part 5 of the draft Mental Health Bill.**

226. Part 5 of the draft Mental Health Bill, if implemented, would only provide safeguards for people being treated in hospital and not to those treated in residential care or nursing homes or in their own homes. Under the draft Mental Incapacity Bill, if a medical practitioner wanted to treat an assenting incapacitated person at home or in hospital, this could be done under the general authority, so long as the practitioner reasonably believed it to be necessary and in the best interests of that patient. Under the best interests test, the medical practitioner would be required to consult with anyone involved in caring for the

<sup>252</sup> See for example Qs 86-87 (Dr Lyons), Q294 (Dr Zigmond)

<sup>253</sup> *R v Bournewood Community and Mental Health NHS Trust ex parte L* [1998] 3 All E R 289, HL at 308

<sup>254</sup> Q709 (Ms Winterton)

<sup>255</sup> Letter from Department of Health to the Clerk of the Joint Committee, 6 November 2003



person and, where appropriate, with an attorney or deputy. While this would probably be satisfactory in most cases, action taken under general authority does not have the safeguards provided by the requirement for a second opinion under the Mental Health Act. We have already suggested in our recommendations relating to the general authority that a second opinion should be obtained for certain treatments when the patient cannot consent, even if they are apparently assenting. Such a safeguard could also apply to serious forms of treatment for physical conditions, to be specified in regulations, as well as to the types of treatment for mental disorder which currently require a second opinion under the MHA.

**227. We recommend that the provisions for obtaining a second opinion currently available to patients detained under the Mental Health Act should be extended to compliant incapacitated patients requiring specified forms of treatment for mental disorder or for physical conditions, whether in hospital or in the community. The Bill should include a regulation making power to specify the types of treatment requiring a second opinion, which can be amended as new treatments are developed.**

## **13 Chapter 13: (Clause 30) Codes of Practice**

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228. Clause 30(1) requires the Lord Chancellor (or whoever takes over the duties and responsibilities of that office) to prepare a Code or Codes of Practice for the guidance of people involved in the assessment of capacity, for people using the various decision-making powers under the new Act, and with respect to any other matters as s/he thinks fit. There has been universal agreement in evidence to the Committee that Codes of Practice will be essential to the proper implementation and operation of the new legislation.

229. We have found it difficult to carry out our task in conducting thorough pre-legislative scrutiny of the draft Bill without having sight of drafts of the Codes of Practice. We were reassured to hear in evidence from Lord Filkin, Parliamentary Under-Secretary of State, that it is the aim of the Department for Constitutional Affairs for the Codes of Practice to be published in draft at the same time as the Bill is introduced in Parliament.<sup>256</sup> **Although we re-iterate our anxiety to keep up the momentum and ensure that introduction of the Bill is not unduly delayed, we recommend that the Bill should not be introduced to Parliament until it can be considered alongside comprehensive draft Codes of Practice.**

### ***Status of the Codes of Practice***

230. Clause 30(6) places a duty on anyone acting in a professional capacity or for remuneration in relation to a person who lacks capacity to “have regard to any relevant Codes of Practice”. Several organisations sought clarification of the legal status of the Codes of Practice and any sanctions which might apply for non-compliance with the codes.<sup>257</sup> One way to strengthen the status of the codes may be to use a formulation of

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<sup>256</sup> Q718 (Lord Filkin)

<sup>257</sup> Ev 203 MIB 1030 para 14.1, Ev 461 MIB 998 para 30, Ev 481 MIB 1060 para 7

words similar to section 7(1) of the Local Authority Social Services Act 1970, which states that local authorities, in the exercise of their social services functions “shall ... act under the general guidance of the Secretary of State”. The binding nature of such guidance has been confirmed by the court so that local authorities may only depart from it with good reason.

231. Following a recent decision of the Court of Appeal it has been established that a Codes of Practice are one essential means by which the State fulfils its obligation to ensure that public authorities act in compliance with the Human Rights Act 1998. Codes of Practice can provide transparency and predictability where human rights compliance requires this in cases where it is impossible to draft the legislation in sufficient detail to cover all circumstances in which the law might apply. The Codes of Practice should therefore be afforded sufficient status consistent with this purpose. All public authorities, which includes professionals and others employed by public bodies, should be under a duty to abide by the Codes of Practice and any departure from the guidance given in the codes should only be justified in exceptional circumstances when full reasons must be given. We seek reassurance that the wording used in the Bill will ensure that the Codes of Practice are afforded sufficient status to comply with human rights obligations.

232. The position is different with regard to guidance issued to assist non-professional or informal decision-makers, such as family members and unpaid carers acting under the general authority. It is essential that family members and carers carrying out such responsibilities are provided with appropriate guidance and assistance, both to promote good practice and also to impress upon them the seriousness of their actions and the need to be accountable for them. We accept that it would be inappropriate to impose on them a strict requirement to act in accordance with the Codes of Practice. **We agree that only those acting in a professional capacity or for remuneration should be under a duty to abide by the Codes of Practice. However, we believe that family members and carers should be strongly encouraged to follow the Codes of Practice.**

***Preparation and revision of the Codes of Practice***

233. Several witnesses drew the Committee’s attention to existing guidance which has already helped to promote good practice and could form the basis of the Codes of Practice under the Bill.<sup>258</sup> We welcome the provision in Clause 30(4) for the preparation of the codes to be delegated in order to build on existing sources of guidance and to make use of the wealth of expertise available, not only that of professionals working with people who lack capacity but also that of people likely to be directly affected by the Bill’s provisions. In particular, we were impressed with the evidence given by organisations of people with learning disabilities and were told of their work in helping to prepare documents in a format accessible to learning disabled people and in providing training for professionals and others working with them.<sup>259</sup>

<sup>258</sup> See for example Ev 457 MIB 997 para 12, Ev 203 MIB 1030 para 7.1

<sup>259</sup> Ev 232 Q645 (Mr MacGiven) Ev 228 MIB 778, Ev 230 MIB 733

234. We hope that the Department will make use of a wide range of expertise, both professionals and those affected by the Bill's provisions, in the preparation and revision of the Codes of Practice. In particular, organisations of people with learning difficulties should be involved in training and producing accessible versions of the codes.

235. We also welcome in clause 30(3) the requirement to consult before preparing or revising a Codes of Practice. It is clearly essential to involve practitioners in identifying issues which should be addressed in the codes. We hope that such consultation will include inviting comments on the draft codes and allowing the results of the consultation to be taken into account before the final versions are laid before Parliament. Lessons may also be learnt from the experience in Scotland, where detailed Codes of Practice have been produced, but which one witness described as being "quite dense".<sup>260</sup> The same witness recommended the Codes of Practice issued under the Disability Discrimination Act 1995 as being "very helpful indeed in giving real life situations".<sup>261</sup>

236. The Law Society of Scotland described to us the "exhaustive on-going multi-disciplinary training relative to the then Bill and now the new Act; ...extensive accessible training materials ... [and] extensive regularly updated guidance".<sup>262</sup> Professor Michael Gunn confirmed the view expressed in many submissions to us that legislation of this sort will rely heavily, not only on clear, comprehensive and accessible Codes of Practice, but also on the training, education and public awareness campaigns that must lead in to and follow on from implementation of the new law.<sup>263</sup>

237. We recognise the efforts already made by the Department of Constitutional Affairs to raise awareness of the issues affecting incapacitated adults, through the Mental Incapacity Consultative Forum and other initiatives. We hope the momentum will be sustained, not only to capitalise on the public and professional interest generated by the publication of the draft Bill but also to inform the preparation of the Codes of Practice.

### ***Content of the Codes of Practice***

238. In a number of submissions to the Committee, concern was expressed that too much detail is being left to the Codes of Practice rather than being specified on the face of the Bill.<sup>264</sup> We have considered some particular concerns about the scope and content of the codes.

### ***Supported decision-making***

239. A key principle of the Bill is the presumption of capacity - that every adult has the right to make their own decisions and is assumed to have capacity to do so unless it is proved otherwise. Some people may need help or support to be able to understand the

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<sup>260</sup> Ev 213 Q583 (Mr Clements)

<sup>261</sup> Ev 213 Q583 (Mr Clements)

<sup>262</sup> Ev 3 Q1 (Ms Craigmyle)

<sup>263</sup> Ev 146 MIB 1187

<sup>264</sup> Ev 173 Q427 (Mr Dixon)



decision they are being asked to make, to know how to make a choice or to be able to communicate, but the need for help and support does not remove their right to make their own decisions.

240. Although the Bill deals primarily with decision-making on behalf of people who lack capacity, many submissions to the Committee stressed the need for greater emphasis on supporting and enabling people to make their own decisions.<sup>265</sup> We were given examples of how people with impaired capacity, even those with profound disabilities, can be helped and supported to make their own choices. Values into Action in particular suggested that “new guidance is needed on the use of supported decision-making to ensure the fullest possible involvement of the person deemed to lack capacity”.<sup>266</sup>

241. Clause 2(3) states that a person is not to be treated as unable to make a decision unless “all practicable steps” have been taken to help the person make a decision themselves. We agree that a Codes of Practice on supported decision-making would be extremely helpful, particularly to provide guidance on the “practicable steps” which should be taken to assist people to make their own decisions and also on the various types of communication aids, therapies and assistance available to help people to communicate those decisions.

### *Assessment of capacity*

242. Clause 30(1)(a) requires the preparation of a code of practice for the guidance of people assessing whether a person has capacity in relation to any matter, but the Bill makes no other specific provision in relation to assessment of capacity. The Making Decisions Alliance (MDA) wrote in its submission that “Given its fundamental importance, coverage of assessment [of capacity] in the draft Bill is alarmingly sparse”.<sup>267</sup> The MDA recommended that the term “assessment” should be clearly defined in statute, in order to clarify when an independent assessment of capacity is required and how, and by whom, it should be carried out. The British Psychological Society suggested that the Bill should specify a “robust, transparent and practical system”<sup>268</sup> for the determination of incapacity and proposed a formal process of registration of persons lacking capacity in relation to certain major decisions.<sup>269</sup> Other submissions pointed out that where any significant infringement of a person’s right to autonomy is contemplated, human rights considerations require a proper assessment to be carried out.<sup>270</sup>

243. As is currently the case under the existing law, the Bill adopts a functional approach to capacity, which means that the question of who should assess capacity, and the test of capacity to be applied, will depend on the particular decision to be made. For most day-to-day decisions, the carer most directly involved with the person at the time the decision has to be made assesses their capacity to make the decision in question. Formal processes are

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<sup>265</sup> Ev 228 MIB 778 Ev 230 MIB 733

<sup>266</sup> Ev 230 MIB 733 para 9(i)

<sup>267</sup> Ev 46 MIB 950 para 5d.5

<sup>268</sup> Ev 101 MIB 817 para 5

<sup>269</sup> Ev 102 MIB 817 para 5.b

<sup>270</sup> Ev 416 MIB 1192

rarely required unless the assessment is challenged, for example by another family member. Where consent to medical treatment or examination is required, the doctor proposing the treatment must decide whether the patient has capacity to consent and should record the assessment process and findings in the person's medical notes. Where a legal transaction is involved, such as making a will or a power of attorney, the solicitor handling the transaction will need to be satisfied that the client has the required capacity to satisfy the relevant legal test, perhaps assisted by an opinion from a doctor. In some situations, case law demands that a doctor should witness a document or otherwise attest to the person's capacity. The draft Bill includes provision to formalise this procedure for Lasting Powers of Attorney (LPAs), by requiring a certificate of capacity at the time the LPA is created.

244. The more serious the decision, the more formal the assessment of capacity may need to be, but whoever assesses capacity must be prepared to justify their findings. Ultimately, if a person's capacity to do something is disputed, it is a question for the court to decide. Cases referred to the new Court of Protection will require formal evidence of the assessment of capacity, either to enable the Court to make a declaration as to whether the person has or lacks capacity or to confirm that the Court has jurisdiction to deal with the matter in question.

245. **Given the diverse range of situations which will be covered by the statutory framework for decision-making imposed by the Bill, we consider that the processes and requirements relating to assessment of capacity would be most appropriately dealt with in a Codes of Practice, as required under Clause 30(1)(a).**

### ***Best interests***

246. In the section of this report on Clause 4 relating to "best interests" (see Chapter 7) we have already commented on proposals put to us to clarify and expand on the factors to be considered when determining best interests. We have acknowledged that, whatever drafting changes are made, there will still need to be more detailed explanations, illustrated by practical examples, in the Codes of Practice.

247. **The Codes of Practice will need to cover, amongst other matters, the concept of best interests itself; the processes and issues involved in considering the factors set out in the Checklist in Clause 4 (including ethical issues such as confidentiality); suggestions of the types of additional factors which may be relevant in different situations and guidance on weighing up competing or conflicting concerns.**

### ***General authority***

248. Major concerns have been expressed to us about the broad scope of powers available under the general authority<sup>271</sup> and the lack of protection for people lacking capacity against decision-makers who abuse those powers.<sup>272</sup> While guidance for people acting under the

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<sup>271</sup> See para 118 (this Report)

<sup>272</sup> See para 120-122 (this Report)

general authority will be essential, we agree that the Codes of Practice alone cannot be relied on to ensure good practice and that restrictions on the use of the general authority must be set out in statute. Our recommendations on this matter are set out in paragraphs 118, 123, 127 and 129.

**249. The Codes of Practice will need to include, amongst other matters, a clear explanation of the general authority as the means whereby practical and legally relevant decisions can be made, in a manner that is enabling and respectful of the person lacking capacity; guidance and examples setting out when it might be “reasonable” to act; the scope of the authority and how it links with other decision-making powers; and the requirement for all decision-makers to be fully accountable for their actions.**

### ***Decision-makers acting under formal powers***

250. Clause 30(1)(c) and (d) require the Codes of Practice to provide specific guidance for donees of lasting powers of attorney and for deputies appointed by the court. We agree that those exercising formal powers under the Bill will need clear and specific guidance about their legal duties and responsibilities and about the extent of their powers.

251. In our discussions on the concept of best interests, we considered a proposal put forward by the Master of the Court of Protection that there should be a comprehensive statement of the standard of conduct required of everyone who acts or makes decisions on behalf of persons without capacity.<sup>273</sup> The Master suggested a number of general obligations which should be imposed on decision-makers in addition to their specific duties, which might include obligations:<sup>274</sup>

- to act reasonably;
- to act diligently;
- to act honestly and in good faith;
- to act within the scope of his or her authority;
- to limit interference in the life of the person without capacity to the greatest extent possible;
- to protect him or her from abuse, neglect, and exploitation;
- to respect and advance his or her civil liberties and human rights;
- to provide such assistance and support as is needed;
- where appropriate, actively to help him or her resume or assume independent or interdependent living;

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<sup>273</sup> See paras 97-98 (this Report)

<sup>274</sup> Ev 184 MIB 1049 para 13



- to involve him or her in all decision-making processes to the greatest possible extent;
- to encourage such participation and to help him or her to act independently in the areas where he or she is able;
- to encourage him or her to exercise whatever skills he or she has, and wherever possible to develop new skills; and
- to exercise substituted judgment by respecting and following his or her wishes, values and beliefs to the greatest possible extent, so far as these are known or can be ascertained, and will not result in harm or be contrary to his or her best interests.

252. We agree that it would be helpful to include in the Codes of Practice a checklist of obligations along the lines set out above, setting out the standard of conduct expected of formal decision-makers. **We recommend that specific requirements of a standard of conduct be included in the Codes of Practice aimed at those exercising formal powers under the Bill.**

### ***Monitoring implementation of the Codes of Practice***

253. The draft Bill contains no specific provisions for monitoring the implementation of the Codes of Practice or keeping the operation of the codes under review. The summary paper on ‘Implementing the Draft Mental Incapacity Bill’ provided to us by the Department for Constitutional Affairs described the supervisory role envisaged for the new Office of the Public Guardian (OPG) in monitoring LPAs and deputies, which will presumably involve consideration of their compliance with the Codes of Practice.<sup>275</sup> **We recommend that the Codes of Practice should provide details of the OPG’s supervisory role and the sanctions which may apply in the event of non-compliance with the codes.**

254. In our comments on the new Court of Protection,<sup>276</sup> we consider the appropriateness of court proceedings in dealing with complaints and disputes about the discharge of functions and use of powers under the Bill. In particular, **we recommend that the Court’s powers should include the power to remove a donee or deputy who is acting incompetently or failing to comply with the guidance given in the Codes of Practice as to the expected standard of conduct. It should be made clear to decision-makers that if their behaviour falls below the standard of conduct set out in the Codes of Practice, the court has power to remove them as attorneys or deputies and if their conduct is criminal, they will face the prospect and consequences of prosecution.**

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<sup>275</sup> Ev 261 (MIB 1222)

<sup>276</sup> Chapter 10

## 14 Chapter 14: Protection against abuse and exploitation

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255. We have been greatly concerned to hear about the extent of abuse and exploitation of people with impaired capacity and the lack of provision in the current law to investigate allegations of abuse or provide adequate protection to people at risk of abuse.<sup>277</sup> The same witnesses suggested to us that the draft Bill contains insufficient provisions to protect vulnerable people from abuse or to bring their abusers to account.

256. In its 1995 report, the Law Commission proposed that local authorities should be given new duties to investigate allegations of abuse and new powers to take emergency protective action where a vulnerable person was thought to be at risk of harm.<sup>278</sup> These measures were intended to achieve a balance between the empowerment of people with impaired capacity as autonomous individuals and support for carers acting on their behalf, with the need to provide appropriate safeguards and protection from abuse and exploitation. In ‘Making Decisions’<sup>279</sup> the Government gave no reason for excluding these proposals from its plans for law reform.

257. The Law Society pointed out to us that the support given to many of the Law Commission’s proposals now contained in the draft Bill, for example the general authority, was dependent on there being appropriate “counter-balancing public law protection rights”,<sup>280</sup> to allow allegations of abuse to be investigated and to provide an effective remedy in cases of abuse. The Master of the Court of Protection also asked us in particular to consider whether the draft Bill has struck the right balance between autonomy and protection.<sup>281</sup>

### ***Arrangements for dealing with abuse***

258. In place of new legislation, the Department of Health, jointly with Home Office, issued guidance in 1999 on developing multi-agency procedures for the protection of vulnerable adults.<sup>282</sup> This guidance places responsibility on local councils with social services responsibilities to play a co-ordinating role in setting up Adult Protection Committees (APCs) to develop local inter-agency policies, procedures and joint protocols, bringing together all the agencies who may come into contact with vulnerable adults. We heard evidence from the Association of Directors of Social Services (ADSS) that while some local authorities have well-established arrangements in place, others have not yet begun to implement the guidance.<sup>283</sup> It was also pointed out that local authorities have not

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<sup>277</sup> Ev 188 Q505 (Mr Lush) Ev 193 Q517 (Professor Williams)

<sup>278</sup> Law Commission No. 23 (1995) Part IX

<sup>279</sup> ‘Making Decisions’, Lord Chancellor’s Department, October 1999, Cm 4465

<sup>280</sup> Ev 214 Q589 (Mr Clements)

<sup>281</sup> Ev 185 para 23 mib 1049

<sup>282</sup> “No Secrets: guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse” Department of Health, 1999. See also [www.doh.gov.uk/scg/nosecrets.htm](http://www.doh.gov.uk/scg/nosecrets.htm)

<sup>283</sup> Ev 178 Q463 (Mr Collingridge)

been resourced for the additional responsibilities given to them under the 'No Secrets'<sup>284</sup> guidance.

259. Several witnesses drew attention to problems with the current arrangements, whether or not APCs have been established. Master Lush told us that the police are often reluctant to get involved, particularly if the allegation is made against a family member who is acting under an Enduring Power of Attorney.<sup>285</sup> Professor Williams referred to the frustration felt by social workers and health care professions who have no powers to intervene even when they are aware that abuse is taking place.<sup>286</sup> The Law Society endorsed both these concerns.<sup>287</sup> In the view of Professor Williams, the current law "does not comply with the Human Rights Act, tolerates financial abuse, tolerates physical abuse, and basically there is nothing that can be done".<sup>288</sup>

### ***The need for additional powers?***

260. In a paper to the Committee on Implementation of the Bill, the DCA described the supervisory role proposed for the new Office of the Public Guardian (OPG). This confirmed that "The OPG's supervisory role would be geared to risk and would intrude as little as possible. The focus would be on supervision of deputies. ... Where there are allegations of possible abuse (of any kind), [OPG] would liaise closely with all of the agencies and individuals involved, including social services, the police, voluntary organisations and Adult Protection Committees".<sup>289</sup> It therefore appears that the new OPG will have a similar remit to the existing Public Guardianship Office (PGO) with no additional powers. However, Lord Filkin confirmed to us that the PGO is currently looking at ways in which the work carried out by its investigation unit can be made more effective.<sup>290</sup>

261. The DCA also described to us the supervisory roles to be played by a range of other bodies in the health and social care fields. Review bodies such as the Commission for Healthcare Audit and Inspection (CHAI) and the Commission for Social Care Inspection (CSCI) will have general responsibilities to monitor and inspect the delivery of health and social care services and undertake some specific investigations where serious concerns have been raised. We also appreciate that initiatives such as the Patient Advice and Liaison Service (PALS) and the Independent Complaints Advisory Service (ICAS) will assist carers and people with impaired capacity who wish to make formal complaints about health and social care services, which may serve to expose abuse in individual cases. However, we heard evidence that both health and local authority complaints procedures are difficult, cumbersome and slow and people with capacity difficulties may not be taken seriously.

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<sup>284</sup> Ev 183 MIB 1213 para 7e

<sup>285</sup> Q506 (Mr Lush)

<sup>286</sup> Q517 (Professor Williams)

<sup>287</sup> Ev 205 Section 2

<sup>288</sup> Q515 (Professor Williams)

<sup>289</sup> Ev 266 MIB 1222

<sup>290</sup> Ev 280 Q752 (Lord Filkin)



262. The Law Society expressed concern that this approach requires clear evidence of impropriety before any action can be taken and stressed the need for more pro-active powers of investigation and intervention.<sup>291</sup> The ADSS proposed that one way of strengthening the ‘No Secrets’ guidance would be to impose on local authorities a statutory duty to intervene where there are reasonable grounds to suspect abuse.<sup>292</sup> It was also suggested that some local authorities would be unable to give priority to establishing APCs and developing protection procedures unless they were placed under a statutory duty to do so.<sup>293</sup>

263. Under Clause 39 of the draft Bill, the Court of Protection will have the power to call for reports, including from a Lord Chancellor’s Visitor. The Public Guardian may also, under Clause 48(d), request a report from a Visitor in relation to a donee acting under an LPA or a court-appointed deputy. Although these powers will enable the Court or the OPG to look into any matters of concern, they are intended purely as a reporting mechanism. The Bill does not provide Visitors with any specific powers of investigation, supervision or intervention. Under the current law, it is a criminal offence for anyone to obstruct a Lord Chancellor’s Visitor in conducting a visit or making a report but there is no similar provision in the draft Bill.

264. By contrast, we were told of the robust mechanisms available under the Adults with Incapacity (Scotland) Act 2000 for monitoring, supervision and investigation.<sup>294</sup> The Scottish OPG holds a register of all interventions carried out under the Act and has specific duties to monitor, supervise and investigate the use of financial interventions, whether by a carer authorised to use the funds of an incapacitated adult, an attorney or a guardian appointed by the court. Local authorities and the Mental Welfare Commission have powers to supervise, monitor and investigate welfare interventions by an attorney or guardian.

265. The organisation Alzheimer Scotland, which was commissioned by the Scottish Executive to monitor and research the implementation of parts of the AWI Act commented: “The [Scottish] Act has been criticised for being over zealous in a bid to reduce the risk of abuse, subjecting genuine carers to more regulation and bureaucracy than necessary”.<sup>295</sup> Nevertheless, it recommended that similar robust systems should be included in the draft Bill, using risk assessment processes to avoid unnecessary intrusions.

**266. We strongly recommend that the statutory authorities should be given additional powers of investigation and intervention in cases of alleged physical, sexual or financial abuse of people lacking the capacity to protect themselves from the risk of abuse.**

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<sup>291</sup> Ev 214 Q591 (Mr Raymond)

<sup>292</sup> Ev 179 Q464 (Mr Collingridge)

<sup>293</sup> Ev 194 Q520 (Professor Williams)

<sup>294</sup> Ev 2 MIB 990 para 6.2, Ev 14 MIB 989, Ev 448 MIB 968 para 3.3.5

<sup>295</sup> Ev 448 MIB 968 para 3.3.5

### ***Switching the burden of proof***

267. The Master of the Court of Protection has suggested to us that a possible remedy would be to allow the burden of proof to shift in appropriate cases of alleged abuse.<sup>296</sup> He gave the example of an elderly woman with vascular dementia giving a door-to-door salesman a disproportionately large amount of money. He suggested that in such cases where an incapacitated person sells property at an undervalue, buys at an overvalue, or makes an improvident gift, the burden of proof should shift to the other party to prove that the person was able to understand the nature and effect of his/her actions. This would provide a means of restitution against an abuser seeking to take advantage of a person whose capacity is in doubt.

268. Similar measures have already been included in the Sexual Offences Bill to deal with cases of alleged sexual abuse against people lacking capacity to consent to sexual relations. Its general definition of consent requires a person to have the capacity to choose whether to agree to sexual activity. The Bill places the responsibility on defendants to have made “reasonable enquiries” to ascertain whether consent exists. The burden of proof is therefore on the defendant to show that the person had capacity to consent to sexual activity, rather than capacity being assumed or merely disregarded.

269. We recommend that consideration be given to allowing the burden of proof to shift in cases of alleged abuse where the victim’s behaviour might indicate a lack of capacity.

270. Professor John Williams suggested<sup>297</sup> to us another approach to extend the scope of the Bill to cover the lack of capacity to make a free choice as a result of undue influence (or unacceptable pressure). It was recognised there is a precedent in the common law. As Professor Williams acknowledged, drafting such a clause would be “immensely complex” and would have to contain significant safeguards to avoid unnecessary intervention. We do not feel confident in recommending such an approach.

### ***Criminal law provisions***

271. Clause 31 of the draft Bill proposes the creation of a new criminal offence where an attorney or deputy or someone who has care of an incapacitated person ill-treats or wilfully neglects that person. While this additional protection is to be welcomed, the Master of the Court of Protection has pointed out that it appears to relate solely to physical ill-treatment and does not cover financial abuse.<sup>298</sup>

**272. We recommend that Clause 31 be extended to include the misappropriation of the person’s property and financial assets.**

273. We also heard of the particular difficulties in obtaining sufficient evidence to secure a conviction in any criminal proceedings, whether for physical, sexual or financial abuse,

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<sup>296</sup> Ev 189 Q508 (Mr Lush)

<sup>297</sup> Ev 200 (MIB 1210)

<sup>298</sup> Ev 184 MIB 1049 para 6

where the main witness has capacity problems.<sup>299</sup> While the Youth Justice and Criminal Evidence Act 1999 provides some assistance to enable people with special needs to give evidence in court, it does not help with the identification of abuse and the gathering of evidence to enable the Crown Prosecution Service to bring a case to court.

274. We recognise that detailed provisions of the criminal law are the responsibility of the Home Office and therefore outside the remit of this Bill. However, we urge continued co-operation between departments to ensure that the state's positive obligation to provide for the protection of vulnerable people is complied with.

## 15 Chapter 15: Medical Research

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275. The Draft Mental Incapacity Bill makes no provision to enable incapacitated adults to take part in medical research. We have received evidence from the BMA, Royal College of Psychiatrists, the British Psychological Society (BPS), and the Law Society claiming that such a clause should be included. We have also received letters from people who would be extremely concerned to see such a clause added to the bill. We realise that "this is an ethically difficult area".

276. We understand that properly-constituted medical research is the process whereby knowledge about a specific disorder or problem is obtained in order to inform the development of new treatments or support strategies that can then be demonstrated to be effective or not through the use of controlled trials. Such information is essential if new treatments are to be developed and if the National Institute of Clinical Excellence (NICE) is to advise whether those treatments should be freely available. If properly-regulated research involving people who may lack capacity is not possible then treatments for incapacitating disorders will not be developed.

277. We are aware of the stringent arrangements necessary before any medical research, particularly that involving human participation, can take place. Most importantly, there is a requirement that all research must be submitted to an ethics committee for their approval. These ethics committees always include lay representation and specifically address significant ethical questions such as that of informed consent.

278. The AWI Scotland Act does include a clause on research. Dr Lyons, the Scottish clinician, told us that the Scottish Act "does permit research involving people with incapacity under certain restrictions. It must be research into the care, treatment, causes, et cetera, of the incapacity itself. It must be research that cannot be performed in people who are capable. It says in the Act that the research must be likely to be of real and direct benefit to the adult."<sup>300</sup> However, Dr Lyons highlighted the difficulty with this legislation stating that: "if what we were going to do was going to be of real and direct benefit, we would be doing it, we would not be researching it".<sup>301</sup> The Royal College of Psychiatrists said that

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<sup>299</sup> Ev 193 Q517 (Professor Williams)

<sup>300</sup> Q73 (Dr Lyons, Professor McMillan, Dr Bowden)

<sup>301</sup> Q73 (Dr Lyons, Professor McMillan, Dr Bowden)



they would support the framework for research set out in Section 51 of the Scottish Incapacity Act.<sup>302</sup>

279. The Royal College of Psychiatrists believes legislation is needed as “common law does not strictly provide such authority, as it cannot be argued that research is necessarily in that incapacitated person’s best interests”.<sup>303</sup> We were reminded that if legal mechanisms prevented or deterred research with such people, then the development of treatments and the undertaking of treatment trials for disorders such as Alzheimer’s disease would be very problematic. The range of medical research involving people with possible mental incapacity was considerable. Other examples include investigating why people with Down’s Syndrome are at such high risk for Alzheimer’s disease, how best to treat the effects of acute brain injury, how to understand and manage problems such as self-injurious behaviour affecting people with autism, the causes of potentially very debilitating mental illnesses such as schizophrenia, or the best treatment of severe brain disorders such as new variant CJD. Research goes beyond the medical field and includes investigating factors influencing the quality of life of people with incapacitating disorders, or how they can be best helped to make decisions for themselves. In all these examples, some of the people involved will have the capacity to consent to research but others may not.

**280. We are aware that research sanctioned by the ethics committees will vary in its invasiveness. It may extend from no more than asking questions of informants to the direct physical or psychological assessment of people with incapacity. It can also include specific investigations such as blood tests or brain scans. Such research interventions will carry with them different levels of potential inconvenience or discomfort. Informants are very likely to have the capacity to decide whether or not to participate. Assessments and many investigations of people with incapacity can only take place with their co-operation.**<sup>304</sup>

281. The evidence we have received has highlighted the tension that exists between the potential benefits of research and the potential for abuse. The well-known abuse of vulnerable people through ‘medical’ experimentation led to the Helsinki Declaration by the World Medical Association in 1964. This Declaration identified the ethical principles that should guide research involving human participants (including those lacking capacity to consent). These principles have been regularly reviewed, most recently in Edinburgh in 2000. Those engaged in medical research involving those who may lack capacity are obliged to adhere to these principles.

282. Throughout our discussions we have considered the moral and ethical considerations of undertaking medical research on those with lacking capacity. Participation in medical research should be based on informed personal consent of the individual involved. We considered whether it is ever appropriate to involve people in medical research who are unlikely to be able to give such consent. We note, as described above, that research that

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<sup>302</sup> Ev 104 MIB 824b para 3.2

<sup>303</sup> Ev 104 MIB 824b para 3.2

<sup>304</sup> Ev 104 MIB 824b para 3.2

includes participants with specific illnesses or disorders is essential if new treatments are to be developed and assessed for effectiveness. This is as true for illnesses that might lead to incapacity (such as Alzheimer's disease) as it was for usually non-mentally incapacitating disorders such as cancer.

283. Dr Nathanson, Director of Professional Affairs, British Medical Association, told us that the lack of such a clause in the Bill would be “denying patients the possibility of a real benefit if they do not have the possibility of participating in research”.<sup>305</sup> However she recognised the difficulty of implementing such legislation and said it would have to be “extremely carefully constructed in a way that ensures that there is no possibility that individuals can be victimised or experimented on or exploited in any way, but providing one tries to build a structure to avoid that, and I think it is possible to make such a structure, then I think there are real benefits”.<sup>306</sup> When a person lacks the capacity to give consent, they should only be involved with medical research, if it is either in their best interests or if it is the only method of conducting research into their particular condition and everyone involved with the person is satisfied that this is a non-exploitative proposal which will not harm or distress the individual involved.

284. We understand that some people with disorders that affect decision-making capacity would be capable of deciding whether or not to participate in research. However a proportion would not. The legal circumstances at present whereby such a person might be involved in research were uncertain as research could rarely be said to be in a participant's immediate best interests and therefore research was not covered by the principles established through common law. We are concerned that if research were to take place in the absence of statute or any regulation the opportunity for abuse would be greater. **It follows that the inclusion of statutory provisions governing such research would enable the ethical requirements that must underpin research involving people with incapacity to be clearly enshrined in statute.**

285. Our attention has also been drawn to the European Clinical Trials Directive 2001, which seeks to implement uniform rules on the clinical trials of medicinal products and to require member states to draft specific legislation to do this, including making provision for the involvement of individuals who cannot consent. While this Directive is limited to trials of pharmaceutical products, it is possible that future European Directives may extend to other forms of medical research and trials of innovative treatment. There is therefore an argument to include in the draft Bill requirements for the authorisation and supervision of research involving people without capacity to consent, in order to comply with the Clinical Trials Directive and any relevant future European Directives.

286. We asked the BMA how such legislation could ensure that incapacitated people were not exploited. Dr Nathanson told us that “we would see the process as probably being based upon research ethics committees looking at protocols, fully understanding ...that one part of their remit is to make sure that individuals who cannot necessarily talk for

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<sup>305</sup> Q247 (Dr Nathanson)

<sup>306</sup> Q247 (Dr Nathanson)

themselves or express their concerns - that it is their benefit and it is protecting them from exploitation".<sup>307</sup> The BPS supported the existing role played by ethics committees, but told us that the decision-making process of committees could be enhanced by legislation. Inclusion in the draft bill would also provide consistency of standards adhered to by the various ethics committees in England<sup>308</sup>

287. The BPS told us that Local Research Ethics Committees (LRECs) should be given powers to reduce the risk of exploitation on incapacitated adults. They told us that "LRECs should be given a formal legislative framework for their rulings in this area. There will be occasions where the research would involve interviewing a relative or carer and would not present unnecessary risk or exploitation of the individual concerned. However the BPS believe that the Mental Incapacity Bill should specifically require LRECs to insist that individual proxy consent be obtained for research participation by incapacitated persons."<sup>309</sup>

288. We conclude that a clause should be included in the Bill to enable strictly-controlled medical research to explore the causes and consequences of mental incapacity and to develop effective treatment for such conditions. This clause must include rigorous protocols to protect incapacitated adults from being exploited or harmed.

289. We therefore recommend that the Bill should set out the key principles governing research, such as those enshrined by the World Medical Association. Those key principles should include the following:

- research involving people who may be incapacitated must be reviewed by a properly established and independent ethics committee and can only proceed if ethical permission is granted.
- where a person has the capacity to consent then his decision whether or not to partake in research must be respected.
- considerable care should be taken to ensure that under these circumstances consent to participate was freely given and not a consequence of coercion.
- the inclusion of people in research, who lacked the capacity to consent, must only occur when such research has the potential for direct benefit to those with that particular problem and could not have been done through the involvement of those with capacity.
- those undertaking research involving people lacking the capacity to consent must respect any indications that a person did not wish to participate (i.e. was dissenting).
- any discomfort or risk involved in the research must be, at the most, minimal.

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<sup>307</sup> Q249 (Dr Nathanson)

<sup>308</sup> Ev 120 MIB 1205 para 14

<sup>309</sup> Ev 120 MIB 1205 para 17



290. We further recommend that the Codes of Practice should set out the specific issues that ethics committees should be obliged to consider when any research includes people who may be incapacitated. These should include:

- Whether the involvement of people who may be incapacitated is justified given the above.
- Whether issues of consent and consultation with others has been properly been considered given the nature of the research.
- Any other matters that seem relevant.

291. We also recommend that the Codes of Practice should define the duties of research ethics committees in relation to incapacitated adults. The Codes of Practice should state that these committees must include people from outside the medical profession.

# 16 Chapter 16: Advocacy

## *The need for advocacy services*

292. There has long been recognition by disability groups, professionals, service providers and service users of the importance of advocacy and the valuable role it can play in supporting people with special needs to access services and enforce their rights. The need for and importance of advocacy services for people affected by the Bill’s provisions was reflected in the volumes of evidence we received, too numerous to identify all of them individually. In particular we were grateful for the background information on advocacy provided by the Making Decisions Alliance<sup>310</sup> and the graphic examples provided by People First<sup>311</sup>, Changing Perspectives<sup>312</sup>, Values into Action<sup>313</sup> and other self-advocacy groups<sup>314</sup> demonstrating how advocacy has helped people with learning disabilities to make their views and wishes heard. We have also heard from organisations representing other groups of people with impaired capacity about the benefits of advocacy to their client groups.<sup>315</sup> All of these organisations stressed the need for a right to advocacy services, both to assist people with impaired capacity to make their own choices and have them respected, and also as an important safeguard to protect people from having control over their own lives taken away unnecessarily and in particular from the risk of abuse.

293. The Association of Directors of Social Services<sup>316</sup> endorsed the need for advocacy services in order to “enhance the citizenship” of people with impaired capacity by enabling them to speak for themselves. Advocacy can also provide assistance to professionals in

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<sup>310</sup> Ev 30 MIB 950. The Making Decisions Alliance is a consortium of 28 organisations working with people who may have difficulty making or communicating decisions.

<sup>311</sup> Ev 228 MIB 778

<sup>312</sup> Ev 226 MIB 71

<sup>313</sup> Ev 733 MIB 951

<sup>314</sup> See for example Ev 315, MIB 690, Ev 334 MIB 746, Ev 340 MIB 777, Ev 361 MIB 821

<sup>315</sup> See for example Ev 475 MIB 1057, Ev 479 MIB 1060, Ev 482 MIB 1061

<sup>316</sup> See for example Qs 429-431, 433 (Mr Dixon),

carrying out their roles and responsibilities in relation to people with impaired capacity. The Law Society<sup>317</sup> described the role advocates can play in assisting people with capacity problems to give clear instructions to their lawyers, and said in summary: “we would say that [advocacy] is actually fundamental to enabling people with capacity difficulties to [obtain] access to justice.” Care UK<sup>318</sup> providers of residential care services suggested that potential conflicts, for example between carers and family members, could be avoided and resolved through the use of independent advocacy.

294. Amongst the few witnesses to express doubt about the usefulness of advocacy was Rescare<sup>319</sup> who gave examples of poor quality advocates who were inexperienced in dealing with people with severe learning disabilities and who could potentially be influenced by their funding sources, such as the local authority. Rescare also counselled against the suggestion that parents and relatives could not act as advocates, since particularly for those with life-long incapacity, family members will have a “unique longitudinal knowledge of their needs, preferences etc”.

295. The Government’s view of advocacy services, at least in relation to people with learning disabilities, has been summarised in the White Paper ‘Valuing People’<sup>320</sup> as follows:

“Effective advocacy can transform the lives of people with learning disabilities by enabling them to express their wishes and aspirations and make real choices. Advocacy helps people put forward their views and can play an active part in planning and designing services which are responsive to their needs. This applies to people with severe and profound disabilities and to the less severely disabled.”

296. **We are convinced that independent advocacy services play a essential role in assisting people with capacity problems to make and communicate decisions; helping them to enforce their rights and guard against unwarranted intrusion into their lives; providing a focus on the views and wishes of an incapacitated person in the determination of their best interests; providing additional safeguards against abuse and exploitation; and assisting in the resolution of disputes.**

### ***A right to advocacy?***

297. The organisations who submitted evidence in support of advocacy services stressed the need for the Bill to provide a statutory right to advocacy for anyone affected by the Bill’s provisions. People First want “a mandatory right to an independent advocate whenever a person’s ability to make a decision is questioned”.<sup>321</sup> The MDA<sup>322</sup> recommended that Government funding should be provided to enable local authorities to

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<sup>317</sup> Q634 (Mr Clements)

<sup>318</sup> Ev 245 MIB 1202 para 4.4 and Q674 (Mr Allen)

<sup>319</sup> Q688 (Dr Brook) and Ev 254 MIB 1217 page 3

<sup>320</sup> Department of Health, *Valuing People: A new strategy for learning disability for the 21<sup>st</sup> century* (2001), para 4.5

<sup>321</sup> Q662 (Mr Lee)

<sup>322</sup> Ev 85 MIB 1188 page 3

commission independent advocacy services to meet the needs of local people affected by the Bill. In particular, they recommended that the Bill should place a duty on health and social care professionals to involve an advocate “when key life-changing decisions need to be taken or when disputes around these situations arise”. In addition, the MDA suggests an independent advocate should be appointed for individuals who have no other formal or informal network of support.

298. We were reminded that there is already provision in statute<sup>323</sup> requiring local authorities to set up a formal system of authorised representatives for disabled people, to make representations about their need for services. However, this provision has never been implemented because of its resource and administrative implications. The Association of Directors of Social Services<sup>324</sup> confirmed to us that while local authorities already fund “a significant element of advocacy”, current resources would not extend to providing a national service. They pointed out that it would not be appropriate for social workers to act as advocates because of the need for independence - to be “completely outside of anybody who has control over resources” and to avoid conflicts of interest.

299. More recently the Health and Social Care Act 2001<sup>325</sup> imposes a duty on the Secretary of State “to arrange, for the provision of independent advocacy services”, but such services will only extend to providing assistance to individuals in connection with complaints about healthcare services. While many Primary Care Trusts commission advocacy services, for example for users of mental health services (and may be required to make specialist advocacy provision for patients subject to compulsory treatment if the draft Mental Health Bill is implemented), the services provided cannot meet current demand let alone extend to all people lacking capacity.

300. Our attention was drawn to recent developments in Scotland<sup>326</sup>, where local authorities are required to develop local advocacy strategies. An initiative promoted this year (2003) as part of the European Year of Disabled People is the creation of the Advocacy Safeguards Agency, funded by the Scottish Executive Health Department in furtherance of the Executive’s commitment to independent advocacy. The overall purpose of this agency is “to make sure that good quality independent advocacy is available to anyone in Scotland who needs it”.<sup>327</sup>

301. In answer to a question<sup>328</sup> about the costs involved if a right to independent advocacy was included in the Bill, Health Minister Ms Rosie Winterton said “... quite frankly, it would be extremely difficult to envisage that there would be the scale of resources available. ... To say that we could look at the whole range of people who would be covered by the Bill and imagine that in every case there may be an advocate would be unrealistic for us”. Lord

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<sup>323</sup> Disabled Persons (Services, Consultation and Representation) Act 1986 ss 1-2

<sup>324</sup> Qs430-431 (Mr Dixon)

<sup>325</sup> Health and Social Care Act 2001, Section 12

<sup>326</sup> Ev 30 MIB 950 para 5b.29

<sup>327</sup> See <http://www.scotland.gov.uk/about/DD/EqualityUnit/00016097/SteeringASA.aspx>

<sup>328</sup> Q732 (Ms Winterton) (Lord Filkin)



Filkin added that this would also be “undesirable” since in many situations within the decision-making structure created by the Bill, there will be no need for a formal advocate.

302. We agree that it would be inappropriate for us to recommend that resources be committed to provide a statutory right to advocacy for all people affected by the Bill’s provisions. However, we recommend that a provision be included in the Bill, similar to that in the Health and Social Care Act 2001<sup>329</sup>, to empower the relevant Ministers to arrange, to such an extent as is considered necessary to meet all reasonable requirements, for the provision of independent advocacy services to incapacitated adults affected by the Bill’s provisions.

303. We recommend that the Government consider setting up an agency, similar to the Advocacy Safeguards Agency in Scotland, with the aim of promoting standards for good quality independent advocacy.

304. We believe that these measures would serve to raise awareness of the importance of advocacy while facilitating, so far as available resources allow, the development of a range of advocacy services, including self-advocacy, citizen advocacy and professional advocacy, to meet the needs of incapacitated adult in a variety of situations. We see no conflict with the role which will continue to be taken by informal advocates (family, friends and neighbours) in promoting the interests of the people they care for.

### ***The role and status of advocates***

305. In paragraph 5 above, we set out the various ways in which advocates may provide assistance to a person with impaired capacity. In order to carry out these varied but essential roles, advocates must be recognised as having a valid status to be involved in decision-making processes and be allowed to represent the views and wishes of the person concerned.

306. We recommend that the Codes of Practice produced under the Bill provide guidance on the appropriate use of advocacy services, in particular suggesting priority situations when it may be essential for an incapacitated person to have access to an advocate.

### ***Standards and quality of advocacy services***

307. Questions have been raised with us about as to how the standards and quality of advocacy services can be maintained.<sup>330</sup> Many advocacy services have their own code of conduct<sup>331</sup> through which individual advocates can be held to account. In particular, advocates must be aware of any potential conflicts of interests, either in relation to the person they are acting for or the source of their finances. Under the procedures we recommend in paragraph 302 above, Ministers could arrange for advocacy services to be

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<sup>329</sup> Health and Social Care Act 2001, Section 12

<sup>330</sup> Ev 87 MIB 1188

<sup>331</sup> See for example UKAN, *Advocacy – A Codes of Practice* (1994)

provided through the commissioning processes of local authorities and Primary Care Trusts. Such contracting arrangements could provide some means of monitoring and ensuring quality standards, so long as the independence of advocacy services from their funding sources can be maintained. The establishment of Advocacy Safeguards Agency as recommended in paragraph 303 would assist in evaluating services and promoting good practice.

**308. We recommend that all organisations commissioning or providing advocacy services to incapacitated adults should have satisfactory procedures in place to ensure that the standards and quality of independent advocacy services are monitored and maintained.**

## 17 Chapter 17: Resources

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309. We identified four aspects to the question of resources relating to the Bill.

- What will the Bill cost? And will appropriate funding for the Bill be available?
- What would be the cost of additions to the Bill which have been suggested by some witnesses – in particular, advocacy?
- Are the necessary resources – such as staff – available to implement the Bill even if the necessary funding for the Bill is supplied?
- What will be the size of the benefits (either in cost terms or terms of the impacts produced) generated by the Bill?

### ***What will the Bill cost?***

#### *Estimate of costs when Bill was published*

310. Cabinet Office guidance<sup>332</sup> says that when a Department presents a Bill to Parliament, it should produce a Full Regulatory Impact Assessment (RIA) setting out with some precision what the costs of the Bill will be. The Full RIA should build on a Partial RIA, produced during consultation on the Bill and setting out as definite estimates of cost as possible.

311. When the Department presented the Bill to Parliament in June 2003, however, they provided no estimates of cost. The Bill was not accompanied by a Full RIA, but only by a Partial RIA and this did not contain any cost estimates at all.

312. The Department told the Committee that they had Treasury agreement to publish the draft Bill before the resources required had been fully assessed and the costs settled.

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<sup>332</sup> *Better Policy Making: A Guide to Regulatory Impact Assessment*, Cabinet Office, paragraphs 3.6, 3.7, 4.2 and 4.3

### *Estimate of costs provided to the Committee*

313. The Department did not provide us with any estimates of costs until 16 October 2003. Even so, these late estimates appear to be highly provisional at best. In written evidence the Department told us that these figures 'are very much initial estimates. Significant refinements are likely before the Bill is introduced to Parliament.'<sup>333</sup> They also said: 'Figures at this stage should be seen ... only as a rough indication of the likely scale of the cost of the Bill.'<sup>334</sup>

314. The Association of Directors of Social Services (ADSS) told us that Local Authorities, on which many of the costs of the Bill will fall, had not done detailed work on costing the implications of the Bill. They told us that the Department for Constitutional Affairs and the Department of Health had only started talking to them in the last couple of months about costs and that they had a very long way to go before they would be able to make detailed estimates.<sup>335</sup> They claimed that consultation with the Department for Constitutional Affairs had not been adequate and that in most respects the process of consultation had not really begun.<sup>336</sup>

315. Given that the Bill has been under consideration for so many years, we fail to understand why the Department were not able to produce more accurate figures, and do not appear to have carried out adequate consultations on likely costs. We regret that the draft Bill was presented for Parliamentary scrutiny without an accompanying assessment of the resource implications. We were surprised that the Treasury should have apparently waived the requirement for a full resource impact assessment to accompany the draft Bill which placed us in the invidious position of having to carry out our scrutiny without any detailed indication of what the Bill might cost.

### *Possible costs of the Bill*

316. Although provisional, the Department's estimates do show that the cost of the Bill will be considerable. Set-up costs will be in the region of £17 million and on-going annual costs a further £18.5 million.<sup>337</sup> Using these figures, we calculate that the present value of the costs of the Bill over a ten-year lifetime would be £171 million.

317. The Department told us that these estimates do not take account of how much was already being spent on mental incapacity through the provision of legal advice and assistance and by the NHS and social care. But, although they had apparently been unable to find out what was being spent in these areas, they had conservatively assumed the expenditure as being zero in their cost estimates. Whatever this current expenditure turns out to be will therefore offset the estimated cost of the Bill. For this reason, the Department

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<sup>333</sup> Ev 464 MIB 1220 pg 11

<sup>334</sup> Ev 464 MIB 1220 pg 11

<sup>335</sup> Q454 (Mr Collingridge)

<sup>336</sup> Q458 (Mr Collingridge)

<sup>337</sup> Ev 464 MIB 1220 pg 11



told us: ‘It is likely that final cost estimates will be lower after [such] expenditure... has been taken into account.’<sup>338</sup>

## *Training*

318. The Department told us:

“We have not anticipated that there would be significant costs arising from implementation because the Bill largely builds upon the current law and best practice.”<sup>339</sup>

319. However, the ADSS told us that: ‘The Bill has significant implications for service delivery and there will be costs associated with implementation.’ The ADSS pointed especially to training costs, which the Department has not explicitly included in its cost estimates. The ADSS said:

“[T]here are considerable training implications for care staff. The arising practice issues need to be included in the new Social Work degree; and in the range of training for non-professionally affiliated staff. It should be noted that the majority of care staff will not have a professional qualification.”<sup>340</sup>

They also said:

‘Significant additional training resources will need to be deployed to ensure that staff operate within the framework of the Bill and Codes of Practice. This will include staff employed directly by local authorities, and those employed in voluntary, [sic] and independent sector who provide services under care contracts with local authorities.’

320. This evidence was reinforced by what we were told by the British Psychological Society’s Division of Clinical Psychology (Scotland). Drawing on its experience with the Adults with Incapacity (Scotland) Act 2000, the Division anticipated ‘a requirement for a huge investment in training’. Without that investment, they warned that a wide range of local interpretations would develop, inevitably leading to inequity.<sup>341</sup>

321. In addition, the Department themselves have subsequently told us that they estimate around 100,00 professionals will need training under the Bill.<sup>342</sup>

## *Other implementation costs*

322. The ADSS forecast that, in addition to extra support costs, such as legal advice and preparation of papers for the Court of Protection:

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<sup>338</sup> Ev 464 MIB 1220 pg 11

<sup>339</sup> Ev 267 MIB 1222

<sup>340</sup> Ev 168 MIB 1040 paragraph 5 Clauses 23-25 paragraph (ii)

<sup>341</sup> Ev 16 MIB 991a paragraph 6 (2)

<sup>342</sup> Ev 284 MIB.1221, enclosure on ‘Remaining Questions as requested by the joint Committee, answer to the fourth question under Resources’

“The introduction of the Bill could require a review of current assessment and care management practice, including risk assessment. These [sic] are concerns that the Bill could result in additional demands on Social Services from the public, relatives and friends, and other care professionals, to intervene in people’s lives when there are signs of mental incapacity.”<sup>343</sup>

### *Appointment of Social Services Directors to make welfare decisions*

323. The ADSS referred to Clause 16 of the Bill, which allows for Directors of Social Services to be appointed to take welfare decisions on behalf of people with mental incapacity as well as financial decisions. ADSS told us that ‘the extension of the powers to welfare decisions is likely to result in additional demands on services which are already at capacity’.

### *Legal aid*

324. The Department’s estimate of costs claims that additional legal aid costs arising from the Bill ‘would be restricted to serious, legal matters so should not increase significantly above current levels’.<sup>344</sup> But the Law Society of England and Wales told us in written evidence that:

“The stated objectives of this Bill will be greatly undermined by the lack of availability of public funding. The need for advance planning for the budget implications is brought to Parliament’s attention so that proper planning can take place and an appropriate enhancement to the legal aid budget identified.”<sup>345</sup>

325. Later, however, in their oral evidence to the Committee, the Law Society admitted that, since no major case of this kind had so far come before the Scottish courts, the legal costs might be less than they had feared.

### *Savings*

326. The ADSS also told us that in some respects the Bill might produce savings or income: for example, if Local Authorities were allowed to levy charges on the property of mentally incapable people for whom they were acting as deputies. They also thought that the Bill might make it easier for Local Authorities to collect debt from people with incapacity and, in some circumstances, might minimise the need for Local Authority intervention by encouraging people to make advance arrangements for the contingency of mental incapacity.<sup>346</sup>

<sup>343</sup> Ev 168 MIB 1040 Appendix 2 paragraph 3.2

<sup>344</sup> Ev 261 MIB 1222 page 11

<sup>345</sup> Ev 203 MIB 1030 paras 9.1 and 9.2

<sup>346</sup> Ev 168 MIB 1040 para 5 Clause 19(7); paragraph 3.9

## ***Cost of Possible Additions to the Bill***

### ***Advocacy***

327. Several witnesses recommended provision for people without capacity to be supported by independent advocates. For example, People First told us that there should be a mandatory right to an independent advocate whenever a person's ability to make a decision is questioned.<sup>347</sup> The ADSS also told us that the best interests of a person without capacity would be promoted by easy access to independent information, advice and advocacy. However, they emphasised that Local Authorities did not have the duty or the resources to secure the provision of support and advocacy.

328. The Minister of State for Health, Ms Rosie Winterton, told us that the Department had not calculated what the costs would be if a facility for independent advocacy was added to the Bill. But she said that, given the range of decisions that would be taken under the Bill and the numbers of people involved, she thought that it was unlikely that the necessary resources would be available.<sup>348</sup>

329. Although we support some extra provision for advocacy, we think that uncertainty about the extent of the Department's commitment to advocacy and lack of any information about the possible costs entailed further illustrates the problems of bringing the Bill forward before proper consultation on cost has been carried out.

### ***Will the resources be available to implement the Bill?***

330. Lord Filkin, the Parliamentary Under-Secretary of State, in a letter to the Chairman of the Committee, Lord Carter, on 16 October, said that work on how the Bill is to be implemented was still in progress:

“Whilst pre-legislative scrutiny has been progressing my Department has been continuing to explore how the Bill might best be implemented. We have begun to map out the necessary processes that would bring effect to the Bill, processes required both by the Bill itself and accompanying non-statutory processes that would support it. To this end, I am working closely with colleagues, in particular at the Department of Health and also in discussion with the ODPM and DWP.”<sup>349</sup>

331. The ADSS raised concerns that Local Authorities might not have enough staff to implement the welfare provisions of the Bill.<sup>350</sup> They told us that, even if they had the money, the problems of recruiting and training the social workers, trainers and administrative staff necessary to implement the Bill were such that it might not be easy to ‘get the bodies’.<sup>351</sup>

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<sup>347</sup> Q662 (People First)

<sup>348</sup> Q732 (Ms Winterton)

<sup>349</sup> MIB 43

<sup>350</sup> Q455 (ADSS)

<sup>351</sup> Qs 468, 469 and 470 (ADSS)



332. The ADSS also pointed out that the Bill imposes no statutory duties for Local Authorities to act. Unless Local Authorities were given adequate resources by central government, they might decide not to implement certain parts of the Bill because they would be unable to divert the necessary resources from carrying out statutory obligations.<sup>352</sup>

333. The ADSS also claimed that Local Authorities would need to be assisted with the legal costs of proceedings before the Court of Protection under the Bill. The costs of one or two complex legal cases could come to more than the cost of a social worker.<sup>353</sup>

334. The Minister of State for Health, Ms Rosie Winterton, told us that the Department for Constitutional Affairs and the Department of Health were still looking at the long term implications of the implementation of the Bill for health and social care staff and the training they would need. She said they were still trying to get a clearer idea of how many staff members and workers would be needed in health and social care as a result of the Bill.<sup>354</sup>

### ***What will the benefits of the Bill be?***

335. Cabinet Office guidance on RIAs says that the Department when it presents a Bill to Parliament should produce an RIA with precise estimates of benefits. This should quantify and place a monetary value on all impacts. In the few cases where this is not possible then the amount of impact should be quantified (e.g.: numbers of people helped, degree of help provided) or at least detailed qualitative analyses of the benefits should be made. The guidance says: '[T]here needs to be enough analysis of impacts to enable Ministers to decide whether or not the benefits justify the costs and for any external scrutiny to take place[.]' The guidance suggests ways in which benefits can be quantified – for example, through surveys or using consultants to estimate benefits.<sup>355</sup>

336. The Department have listed the benefits they considered the Bill would produce. But they claim that these benefits would be impossible to quantify, although 'they are undoubtedly important to the daily living of millions of people'.<sup>356</sup> The Department have provided no estimate of the quantum of benefit, even in the form of ranges of numbers of people affected or the degree of impact. Nor have they provided any detailed qualitative analysis of benefit.

337. We are not convinced that no action could have been taken to quantify benefits or produce a qualitative analysis. The Cabinet Office guidance makes clear that benefits of many kinds can and should be appraised and we believe that an attempt ought to have been made to give us an appraisal of the likely material benefits of the Bill.<sup>357</sup>

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<sup>352</sup> Q456 (ADSS)

<sup>353</sup> Q457 (ADSS)

<sup>354</sup> Q731 (Ms Winterton)

<sup>355</sup> *Better Policy Making: A Guide to Regulatory Impact Assessment*,

<sup>356</sup> Ev 261 MIB 1222 page 4

<sup>357</sup> *Better Policy Making: A Guide to Regulatory Impact Assessment*, Cabinet Office, paragraph 4.3 and Annex 4

338. We note that Lord Filkin told the Committee that part of the Department's assessment on resourcing would be to consider to what extent best practice was currently met among care professionals and whether there was a gap between average and best practice.<sup>358</sup> This in itself involves an assessment of benefit, since one of the key benefits claimed for the Bill is that it will raise standards to the level of best practice which the Department are apparently intending to quantify.

## **Conclusions**

339. The Department have not produced reliable estimates of the cost of the Bill or adequately consulted on likely costs. They have provisionally estimated a cost equivalent to a present value of £171m over ten years and some witnesses have identified still further costs. However, we recognise that not all the costs predicted by witnesses will necessarily add to the overall burden on taxpayers at national or local level; there may also very well be offsetting savings.

340. Given that the Bill has been under consideration for so many years, we fail to understand why the Department were not able to produce more accurate figures and do not appear to have carried out adequate consultations on likely cost. We regret that the draft Bill was presented for Parliamentary Scrutiny without the accompanying assessments of the resource implications. We were also surprised and disappointed that the Treasury should have waived the requirement for a full resource impact assessment of costs and benefits to accompany the draft Bill. As a result of these factors, we have been placed in the invidious position of having to carry out our duty of scrutiny without any detailed indications of what the Bill might cost or what the quantum of benefits it will lead to might be.

341. In the absence of such indications, we regret that we are unable to reach any conclusions on the resource impact of the Bill. Many of the benefits of social legislation are unquantifiable. Nevertheless, the Department's failure to provide proper estimates of costs and likely benefits has impaired the process of pre-legislative scrutiny and made it impossible for us to judge whether the benefits of the Bill may outweigh its costs or whether the likely cost might benefit people without capacity more effectively in other ways. Nor is it clear to us whether adequate trained personnel will be readily available to ensure that the Bill is implemented effectively. We can only urge that these aspects are exposed to the most rigorous scrutiny when the Bill itself comes before both Houses.

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<sup>358</sup> Q730 (Lord Filkin)

## 18 Chapter 18: Access to Information

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### ACCESS TO INFORMATION

342. Although it was not specifically raised with us in evidence, we noted that the draft Bill does not deal with Access to Information about those lacking capacity to make decisions. This seemed to us to be an important and potentially difficult issue which appeared to have implications for the way in which parts of the draft Bill might work out in practice.

343. We presumed that those who lack capacity would be entitled to the same rights of confidentiality about their personal affairs as those who have capacity. But we wondered whether laws like the Data Protection Act or the conventions in professional guidance which enshrine that right might cause problems for those who are trying to help persons lacking capacity to take decisions in their best interests.

344. We assumed that donees appointed to manage financial affairs under Lasting Powers of Attorney would have full rights of access to financial information about those for whom they have responsibility, as would Deputies appointed by the Court of Protection. But it was not clear whether donees and Deputies would have those same rights under the draft Bill to information related to medical and welfare decisions.

345. We also foresaw problems for the wider range of persons whom the draft Bill envisages acting under the general authority on behalf of those lacking capacity. We noted that the draft Bill placed responsibility on them to consult with relevant bodies or persons in determining the incapacitated persons best interests. But, without such rights of access to information, those bodies or persons could feel bound to refuse them access which they needed to information regarded as confidential.

346. This seemed to us to be likely to inhibit the simplified decision-making and enhanced consultation which the Bill was trying to encourage. It might well result in decisions being delayed while applications were made to the Court of Protection, which would in turn add to the Court's workload.

347. We thought it might create a particular problem for advocacy services, because they have no defined status under the draft Bill. We also wondered how it might affect the investigative powers of the Office of the Public Guardian or the effectiveness of the new Adult Protection Committees to be set up jointly by the Department of Health and the Home Office under the Government's "no secrets" policy.

348. The Chairman therefore wrote to Lord Filkin, the Under-Secretary of State for Constitutional Affairs at the Department for Constitutional Affairs, with a copy to Mrs Rosie Winterton, the Minister of State at the Department of Health, seeking clarification.<sup>359</sup>

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<sup>359</sup> Ev 284, MIB 1221



349. Lord Filkin replied acknowledging that access to information, confidentiality and data protection were both important and difficult issues for those lacking capacity. He stated that these issues did not feature explicitly in the current draft Bill because they would “largely be dealt with by consequential amendments and by guidance”<sup>360</sup> He added that consequential amendments would be included in the Bill when it was introduced.<sup>361</sup>

350. He went on to say that, according to guidance issued by the Information Commissioner, a request for access could be made, under the provisions of the Data Protection Act 1998, on behalf of someone lacking capacity where there was an Enduring Power of Attorney or authority from the Court of Protection. He indicated that this guidance might relate to access to clinical records by someone authorised under an Enduring Power of Attorney. But he added that “it would be wrong to assume that this will always encompass decisions about treatment and care”.<sup>362</sup> He referred to orders made under the Data Protection Act which enable Court-representatives to request access to information on behalf of someone who is incapable “providing that certain information is not disclosed to the representatives”<sup>363</sup>

351. Lord Filkin acknowledged that the draft Bill proposed new wider functions under Lasting Powers of Attorney and for court-appointed Deputies. The Department intended to consult the Information Commissioner with a view to amending his guidance. The intention would be to allow requests for access to be made by persons having those powers. He added “consideration is being given to the extent to which financial LPAs should be able to access health and welfare information and vice versa”.<sup>364</sup> He also promised to “revisit the 2000 Orders and consider whether these will require amendment in the light of the Bill.”<sup>365</sup>

352. Lord Filkin also stated that the Department proposed to include powers in the Bill related to the health records of deceased persons. These would be similar to those of the Adults with Incapacity (Scotland) Act 2000 which enable those acting on behalf of persons without capacity who had an interest in the estate of a deceased person to have access to health records.<sup>366</sup>

353. Access to information by those acting under general authority was described by Lord Filkin as “more difficult because there is not one clear person with authority to act”. He suggested that the situation would be the same as that which currently applies to the Common Law:

“At present information is shared on a ‘need to know’ basis and guidance for NHS staff, ‘Confidentiality: NHS Codes of Practice’, has now been published following a

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<sup>360</sup> Ev 496 MIB 1225

<sup>361</sup> Ev 496 MIB 1225

<sup>362</sup> Ibid

<sup>363</sup> Ibid

<sup>364</sup> Ibid

<sup>365</sup> Ibid

<sup>366</sup> Ibid

public consultation. The Code has been endorsed by the British Medical Association, General Medical Council and the Information Commissioner and can be found at [www.doh.gov.uk/confiden](http://www.doh.gov.uk/confiden). Health and social care organisations operating under best practice have drawn up information sharing protocols. For example, the ‘No Secrets’ document requires Adult Protection Committees to draw up common agreements relating to confidentiality.

“Where information is held under the common law duty of confidentiality, it must only be disclosed for the purposes that it was collected for unless there is explicit consent from the subject, a statutory basis for disclosure or a robust public interest justification for the disclosure. Regarding this latter justification, it is accepted that where there are concerns about abuse and vulnerable people are at risk, then absolute guarantees of confidentiality cannot be given”.<sup>367</sup>

354. Finally, Lord Filkin said:

“Our developing work on the Bill is leading us to examine further whether these current arrangements shown would be adequate under the Bill, perhaps supplemented by clear guidance or whether they will just have a fresh look at these policies. We will continue to investigate this”.<sup>368</sup>

355. This appears to us to be yet another area where the Department has introduced the draft Bill before taking full account of the potential implications. In this case, the issue is not mentioned on the face of the draft Bill at all. As with the preparation of draft Codes of Practice and adequate assessment of resource implications, it is quite clear that a great deal remains to be done which we would want to see done properly. But we are equally keen not to see the Bill unduly delayed.

356. We regret that the Department do not appear to have adequately addressed the important, though admittedly complex, issues involving access to information to those acting on behalf of people lacking capacity. We welcome the Department’s assurance that work is in hand to resolve these issues and that consequential amendments will be included in the Bill when it is introduced. We hope that the implications can be thoroughly investigated and adequately tackled in the consequential amendments and in the Codes of Practice. But we also hope that this will not unduly delay presentation of the Bill.

## 19 Chapter 19: Jurisdiction

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### JURISDICTIONAL ISSUES

357. We noted that the draft Bill made no reference to how, if implemented, those parts which are different from the current Scottish legislation might affect those domiciled in

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<sup>367</sup> Ibid

<sup>368</sup> Ibid

one jurisdiction if decisions were required on behalf of somebody lacking capacity while in the other jurisdiction. Clearly this issue is not restricted to the draft bill however we felt it important to clarify the Government's intentions in this area. We raised this during oral evidence given by Lord Filkin, Parliamentary Under-Secretary of State, Department for Constitutional Affairs, and Mrs Rosie Winterton, the Minister of State at the Department of Health.<sup>369</sup> We gave a possible example of somebody living in England who had made an advance decision to refuse treatment and appointed a donee under an LPA who suffered a medical emergency and lost capacity while on holiday in Scotland.

358. Ms Claire Johnston, the Head of Legal Advice and Legislation Division of the Department for Constitutional Affairs, described this as "one of the areas where the draft Bill does not cover the ground and will have to". Matching provisions of those of the Scottish Act would need to be added to the Bill before introduction. She intimated that the issue of domicile could be complicated by considerations of property ownership. But, as a general principle, the law of the country in which the person concerned was habitually resident should apply. Lord Filkin undertook to write to the Committee on that point.<sup>370</sup>

359. The response was contained in Lord Filkin's letter dated 7 November 2003 to Lord Carter in which he said:

"our intention is to provide rules in the Bill to match those in the Adults with Incapacity Scotland Act 2000 and to be consistent with the Hague Convention on International Protection of Adults 2000. These provisions on private international are technical and will (be) inserted into the Bill for introduction".<sup>371</sup>

360. He added:

"in relation to Lasting Powers of Attorney, the general position would be that an attorney appointed in England would be able to act on the incapacitated adult's behalf in Scotland. In general the law that applies would be that of the incapacitated adult's habitual residence at the time when the LPA was made. English law would be applied to matters such as whether the LPA is valid. However, the manner in which the attorney can make his decisions is likely to be governed by Scottish law.

"In relation to the application of the advance directive (sic), the Scottish administrative and judicial authorities generally would apply Scottish law. The authorities are empowered to apply the law of England and Wales if it is in the adult's best interests and if the circumstances demonstrate a substantial connection to England and Wales. The Scottish authorities would take an overall view of the situation. It may be more likely, where it is an emergency situation, that Scotland would take a pragmatic approach and apply its own law. That would mean the doctor in charge doing what is reasonable in the circumstances although the

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<sup>369</sup> Q23/24 (Mr Ward)

<sup>370</sup> Ibid Q23

<sup>371</sup> Ev 496 MIB 1225



incapacitated adult's representative could apply to court for an order if they wished to do so".<sup>372</sup>

361. We were rather surprised that the Department had not included in the draft Bill any consideration of the jurisdictional implications of the different Scottish legislation for those domiciled in one jurisdiction who suffer incapacity and require decisions to be made while in the other. We acknowledge that legal complexities might be involved in some cases and welcome the Department's confirmation that they intend to provide adequately for this aspect in the Bill when it is introduced.

## 20 Chapter 20: Change of Title

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362. Finally, several witnesses have suggested to us that the title "Mental Incapacity Bill" was inappropriate and had negative connotations. They argued that the draft Bill was intended to recognise and give effect to the right to make decisions. They preferred "Mental Capacity Bill" which they saw as a more accurate description of the Bill, as well as more positive and reassuring.<sup>373</sup>

363. We agree that the test of mental capacity, rather than incapacity, is central to the Bill. The question of perception is even more important. The Bill must strike the right note. It should avoid the pejorative implications of incapacity and instil confidence in those it is intended to serve.

364. We looked at possible alternatives, such as "Assisted (or Proxy) Decision Making" but preferred the simple but accurate change from "Incapacity" to "Capacity". We hope that such a change might also symbolise the much-needed change in public understanding and attitudes to which we refer in Chapter 1.<sup>374</sup>

365. Accordingly, we recommend that consideration be given to changing the Bill's title to the "Mental Capacity Bill".

## Conclusions and recommendations

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1. We recommend that consideration be given to a new procedure for setting deadlines for Joint Committees carrying out pre-legislative scrutiny to enable them to give full and proper consideration to all the issues involved and to allow those wishing to offer evidence to the Committee a fair and adequate opportunity to do so. (Paragraph 22)
2. We appreciate that this Inquiry has given the Government much more food for thought about the Bill. We also recognise that the difficulties and implications raised later in this Report will need to be dealt with in consequential amendments. Nevertheless, we would be extremely disappointed if the Government felt unable to

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<sup>372</sup> Ibid

<sup>373</sup> Ev 17 September Q166, (Mr Broach) 21 October Q653 (Ms. Aspis) and Q674 (Mr Allen)

<sup>374</sup> See paragraphs 30 and 31

continue to give the Bill due priority. Those whom it is intended to help have waited long enough and deserve to have the benefits which the new legislation can bring in the very near future. (Paragraph 23)

3. We concur with the widely-held view that a new Bill is needed to provide a comprehensive statutory framework for assisting those lacking capacity to make decisions for themselves wherever possible and for proper decisions to be made by others on their behalf where that is not possible. Even so, legislation can only go so far. It must be accompanied by changes in attitude which recognise the rights of those lacking capacity and the need to instil respect and good practice in dealing with them. The Bill must aim to preserve a satisfactory balance between enablement and protection (Paragraph 30)
4. We welcome the Department's commitment to give further consideration to the possibility of incorporating a statement of principles on the face of the Bill. We believe that such a statement inserted as an initial point of reference could give valuable guidance to the Courts, as well as helping non-lawyers to weigh up difficult decisions. Evidence given to us indicates this would be welcome to a wide range of those who have to deal with the problems of substitute decision-making in practice. We also believe that such a statement would be valuable in helping to frame the Codes of Practice based on the Bill. (Paragraph 43)
5. We further recommend that the statement of principles should include the following:
  - Every adult has the right to make his/her own decisions and must be assumed to have capacity to do so unless it is proved otherwise
  - Everyone should be encouraged and enabled to make his/her own decisions, or to participate as fully as possible in decision-making, by being given the help and support s/he needs to make and express a choice
  - Individuals must retain the right to make what might be seen as eccentric or unwise decisions
  - Decisions made on behalf of people without capacity should be made in their best interests, giving priority to achieving what they themselves would have wanted
  - Decisions made on behalf of someone else should be those which are least restrictive of their basic rights and freedoms". (Paragraph 44)
6. We are of the opinion that under the proper interpretation of article 2, the State has a secondary obligation to protect life, but an individual can choose not to uphold that right. Accordingly, the mechanisms under the draft Bill, which permit the refusal of consent to the carrying out or continuation of treatment, in accordance with the wishes of the patient, do not contravene article 2 of the European Convention on Human Rights. (Paragraph 53)
7. Although we have made recommendations that access to the Court of Protection should be further enhanced for persons lacking capacity, we are of the opinion that

there are sufficient mechanisms provided under the draft Bill to ensure that persons lacking capacity receive a prompt, fair and public hearing. (Paragraph 57)

8. Accordingly, we are of the opinion that the arguments put to the Committee that the draft Bill violates the rights enshrined in article 3 are without merit. In agreement with the Joint Committee on Human Rights, we conclude that the draft Bill provides sufficient safeguards to ensure that the right to be free from degrading treatment is protected. (Paragraph 61)
9. We agree with the definition of capacity and the additional clauses under Clause 1 of the draft Bill. We support the principle of presumption of capacity which underpins the draft Bill. We note the functional approach adopted by the draft bill when allied to Best Interests is intended to provide protection to those lacking capacity. In this context, we believe that every effort should be made in both the Bill and in the Codes of Practice to ensure that this Bill is seen as enabling rather than restricting. (Paragraph 66)
10. We recommend that the current clause 3 in the draft Bill before us becomes either clause 2 of any new draft, if our recommendations as to the inclusion of the general principle is accepted; or if not, then the current clause 3 should be clause 1 of any new draft Bill. This is because it better reflects the positive nature of the Bill's purpose and will increase confidence in the operation of this legislation. (Paragraph 67)
11. We see the need for recognising the issue of 'general incapacity' in the draft Bill in a way that will not undermine the primacy of the functional approach and have recommended accordingly. We endorse the criteria of capacity set out in Clause 2 of the draft Bill for assessing whether a person is unable to make a decision and therefore lacks capacity. But we recommend that consideration be given to recognising the issue of 'general incapacity' in the draft Bill in a way that will not undermine the primacy of the functional approach. (Paragraph 68)
12. We recommend that the Codes of Practice should state clearly that all relevant parties must use appropriate strategies to maximise the chance that persons will have the capacity to make decisions. This might include using specific communication strategies, providing information in more accessible form, or treating an underlying mental disorder to enable a person to regain capacity. (Paragraph 70)
13. We endorse the functional approach to the determination of incapacity and the need to demonstrate 'an impairment of or a disturbance in the functioning of the mind or brain in asserting whether a person's capacity is temporary or permanent. We do not see the need to distinguish in the Bill between the temporary or potentially permanent nature of incapacity. (Paragraph 71)
14. We recommend that the Codes of Practice should set out clearly the need for evidence on both 'impairment of or disturbance in mental functioning' and of lack of capacity, as defined in the draft Bill, and the appropriate means of determining that evidence in the best interests of the person concerned so that the criteria against which an appeal might be judged are transparent. (Paragraph 76)



15. We recommend that the Codes of Practice should make clear that those acting under the General Authority or an LPA must appreciate the concept of capacity/incapacity and be fully aware of the responsibilities thus placed on them when carrying out or assisting decision-making on behalf of any person who is considered incapacitated. While it would be unreasonable to expect all those acting under the General Authority to have the necessary knowledge to determine that person's capacity to make any given decision, it is reasonable to expect them to take appropriate advice and have appropriate people to assist them where necessary. The Codes of Practice must set out a framework on these matters which is readily understandable to lay persons. (Paragraph 77)
16. We considered carefully the dilemma created when a person with apparent capacity was making repeatedly unwise decisions that put him/her at risk or resulted in preventable suffering or disadvantage. We recognise that the possibility of over-riding such decisions would be seen as unacceptable to many user groups. Nevertheless, we suggest that such a situation might trigger the need for a formal assessment of capacity and recommend that the Codes of Practice should include guidance on:
  - whether reasonable doubt about capacity and the potentially serious consequences of not intervening indicated the need for an appropriate second opinion;
  - circumstances in which the statutory authorities should be responsible for providing a level of support as a safeguard against abuse; and
  - where there was genuine uncertainty as to capacity and an urgent decision was required to prevent suffering or to save life, the benefit of doubt would be exercised to act in that person's best interests in relation to any assessment of capacity. (Paragraph 78)
17. We take the view that the general principles set out at the start of the Bill should confirm that any act done for, or any decision made on behalf of a person who lacks capacity must be in the person's "best interests", and agree that statutory guidance on determining best interests should be included in the Bill. (Paragraph 83)
18. We agree that no list of 'best interest' factors can ever be comprehensive or applicable in all situations. We therefore endorse the approach recommended by the Law Commission that a checklist of common factors to be considered in all cases should be set out in statute. However, it should be made clearer in the Bill that, in addition to these common factors, all other matters relevant to the particular incapacitated individual and the particular decision must also be considered. (Paragraph 85)
19. In the context of the comprehensive decision-making framework created under the draft Bill, we concluded that the concept of benefit may be too prescriptive if added to the checklist. (Paragraph 86)
20. we concluded that the addition of the word personal to best interests would not provide any better clarification and indeed might cause confusion. (Paragraph 87)

21. We do not recommend any weighting or giving priority to the factors involved in determining best interests. It will be important for the Codes of Practice to provide guidance on how judgements about best interests may be reached, particularly where there are conflicting or competing concerns. (Paragraph 89)
22. We seek reassurance that the form of words used in the Bill will require a person's values to be given due weight. (Paragraph 90)
23. We considered it would be too onerous on relatives, carers and other informal decision-makers to require an understanding of human rights legislation when determining best interests. The Codes of Practice and any Departmental guidance issued to the general public should explain the relevant human rights considerations. (Paragraph 91)
24. We consider that specific provision should be made to confirm that consultation with people close to the incapacitated person will include consideration of their views on what is likely to be in that person's best interests. In advance of the legislation anticipated on the status of civil partners we would expect the expression 'people close to' to include civil partners. (Paragraph 92)
25. We recommend that the drafting of Clause 4 be amended to impose a requirement on decision-makers to seek the least restrictive option, and to specify that, in determining best interests, account must be taken of all the factors set out in the checklist. (Paragraph 94)
26. We take the view that a requirement on decision-makers to seek the least restrictive option would involve having to consider whether any intervention at all was necessary. We therefore see no need for a specific "no intervention" provision other than in relation to court proceedings. (Paragraph 96)
27. We strongly recommend that the requirements of a standard of conduct be included in the Codes of Practice aimed at those exercising formal powers under the Bill. We also recommend that the Department should issue clearly understandable guidance to informal decision-makers on the standards of conduct expected. (Paragraph 98)
28. We seek reassurance that a common law duty of care would apply to all decision-makers under the Bill and ask that consideration be given to imposing a duty of care through express statutory provision. Here, too, the Department will need to issue guidance to informal decision-makers on the expected standards of conduct. (Paragraph 99)
29. We recommend that the Codes of Practice should explain more clearly the circumstances in which reasonable belief should be relied upon. (Paragraph 102)
30. We recommend that clauses 6 and 7 be redrafted to clarify the legislative intent of the general authority, in order to counter what appear to be widespread misunderstandings of the concept and its purpose. It might also be helpful for the Department to consider an alternative to the term 'general authority' which would avoid its misleading connotations and clarify that it is intended to convey permission

to act in the incapacitated person's best interests in circumstances currently covered by the Common Law. (Paragraph 111)

31. We recommend that the Department should clarify the term 'care' in clause 6 (1) and in any guidance given under the Codes of Practice. (Paragraph 112)
32. In addition, we recommend that a sustained and comprehensive training programme for professionals, and a public information campaign for informal carers should be implemented, in order to provide these groups with an accurate understanding of the general authority. (Paragraph 113)
33. We recommend that in re-drafting clause 6 the Department should emphasise the over-riding importance of the best interests of the person concerned, as defined in clause 4. (Paragraph 115)
34. We are concerned that the provision of the general authority should not undermine the 'enabling' ethos of the draft Bill (Paragraph 116)
35. We recommend that a reasonable belief should be objectively held. (Paragraph 117)
36. We strongly recommend a redrafting of the clauses concerning the general authority in order to clarify that its use is intended to be limited to day-to-day decision-making and emergency situations. (Paragraph 119)
37. We recommend that the Codes of Practice relating to the general authority should include a specific reminder that all practicable steps must be taken to help an incapacitated person contribute towards the process of every decision made on their behalf, however minor. (Paragraph 123)
38. We conclude that the Codes of Practice accompanying the draft Bill should emphasise that all persons undertaking actions or decisions under the general authority must be aware that they may subsequently be called upon to justify their actions. They should therefore maintain sufficient records in order to be able to show that their actions were reasonable and in the best interests of the person in question. (Paragraph 125)
39. We disagree with Lord Filkin's assessment. We recommend that consideration be given to imposing a statutory requirement for an independent second medical opinion to be sought in relation to the need for serious or invasive forms of medical treatment. Furthermore we conclude that greater availability of advocacy services would provide a counter to the potential for an excessive or inappropriate use of the general authority (Paragraph 127)
40. We recommend that the Bill makes provision for a Regulation making power to enable further specific decisions to be excluded from the general authority and therefore always taken to the Court of Protection. This should include:
  - those decisions currently requiring court authorisation such as requests for the sterilisation of people lacking the capacity to consent;



- the withdrawal of artificial nutrition and hydration from patients in a persistent vegetative state;
  - any procedure of an experimental kind that might carry significant benefits but which also carries significant risks (a situation exemplified by recent attempts to treat a person with new variant CJD); and,
  - significant decisions concerning the management of an incapacitated person's financial affairs. (Paragraph 129)
41. We recommend that a right to a second opinion in cases of disagreement which have not been resolved through discussion be included on the face of the draft Bill. (Paragraph 130)
  42. We accept the value of mediation services and would like to see reference in the Codes of Practice accompanying the draft Bill to their utility as an alternative mechanism of dispute resolution. In situations where strong disagreements remain over what is in a person's best interests, the dispute should always be referred to the Court of Protection. (Paragraph 131)
  43. We recommend that clause 7 be redrafted to specify that detention can only be justified in a situation of urgency (including an emergency) and that the period of detention should be as short and least restrictive as possible. (Paragraph 132)
  44. We welcome Lord Filkin's acknowledgement that the Department needs to look again at the way in which the general authority is set out in the draft Bill. Unlike the Adults with Incapacity (Scotland) Act 2000 the general authority ensures that all decisions relating to personal care and health matters are brought within a statutory framework. Despite our concerns, we are convinced that with greater clarification of the intention and scope and with wider and more rigorous safeguards, the general authority would significantly improve the legislative framework for substituted decision making in England and Wales. (Paragraph 133)
  45. We recommend that the Bill should make clear whether it is intended that personal welfare decisions, excluding those relating to medical treatment, may be taken when a donor retains capacity. Further, clarification of the extent and limitation of the powers, as well as adequate guidance and training for donees, are also strongly recommended. (Paragraph 144)
  46. Whilst we support the intention of the draft Bill to allow individuals the freedom to choose their donee(s) when making an LPA, we recommend that further guidance is provided to warn donors of the potential for conflict. Furthermore, we recommend the inclusion, in Codes of Practice, of an additional safeguard mechanism by which the Court of Protection or the Public Guardian could monitor the use of LPAs with a view to preventing the abuse and exploitation of a donee's powers. (Paragraph 150)
  47. We strongly recommend that an express duty of care is incorporated into the draft Bill in respect of donees acting under an LPA (and for Court Appointed Deputies). We further consider that a greater degree of accountability is required from those groups in order to limit the potential for abuse of their powers and therefore, we

recommend the exploration of effective methods to achieve that end. In particular, we recommend that specific requirements in the form of a standard of conduct should be included in the Codes of Practice, aimed at those exercising formal powers under the draft Bill. (Paragraph 154)

48. We have concluded that the proposed system requiring the registration of LPAs before use will assist in monitoring the use of LPAs and detecting possible abuse. However, we recommend that donees should be placed under an obligation to notify both the donor and the Public Guardian that the donor is, or is becoming incapacitated, thereby putting this information on the public record and opening it up to challenge. We further recommend that guidance should be provided to assist financial institutions to deal with the operational realities of LPAs. (Paragraph 157)
49. We believe that the additional safeguard of requiring two additional persons to witness the certification of capacity should be included where there are no named persons for notification of the registration of an LPA. (Paragraph 159)
50. We recommend that further guidance should be provided to assist the Court of Protection in deciding when a single order is more appropriate than the appointment of a deputy. (Paragraph 164)
51. We strongly recommend that further consideration is given to the provision of independent advocacy services and other means of enabling people lacking capacity to participate as fully as possible in any hearing affecting their rights and entitlements. (Paragraph 170)
52. We seek assurances that public funds will be made available to ensure that the Court of Protection is sufficiently accessible for those with limited assets. Furthermore, we seek clarification as to the types of cases for which legal aid will be provided to mentally incapacitated applicants and alternative remedies for those cases which will not qualify. (Paragraph 173)
53. We believe that further guidance is required for deputies as to the standard of conduct they must maintain in the operation of their duties. (Paragraph 180)
54. We strongly urge that the provisions allowing deputies to consent to treatment be restricted to exclude the withdrawal or refusal of life-sustaining treatment. Unless there is a valid LPA or advance decision expressing the individual's wishes in relation to the subject, decisions relating to the carrying out or continuation of life-sustaining treatment should be referred to the Court of Protection for determination. (Paragraph 184)
55. The Committee strongly recommend that it should be made clear on the face of the Bill which decisions or acts should fall under the remit of a court appointed deputy and not under the general authority. Furthermore, guidance should be provided to family members, carers and others exercising the general authority as to the point at which it would be appropriate to apply to the Court of Protection for the appointment of a deputy. (Paragraph 187)

56. We recommend that the Bill should permit the making of advance decisions to refuse treatment. We recognise the genuine and deeply-felt concern of those who have moral objections to any decision being taken that could end life, but that right is recognised in law for those who are capable of making such decisions and we think it is right that the Bill should provide for those who wish to do so to have the legal means to have that decision respected should they become incapable. In doing so, the Bill should aim to set standards for good practice and ensure a means of challenge under circumstances where there were disagreements that could not be resolved (Paragraph 203)
57. Many of the fears which have been raised with us about possible connections between the draft Bill and euthanasia appear to be misplaced. Nevertheless, in acknowledgment of the strength of feeling that clearly exists on this issue and in the hope that such misplaced fears do not detract attention from the many worthwhile aspects of the draft Bill, we recommend that additional assurance should be offered by the inclusion of a paragraph in the Statement of Principles we have recommended, or by an additional clause in the Bill, to make clear that nothing in the Bill permits euthanasia or alters the law relating to it. (Paragraph 204)
58. In most circumstances we believe that it would be reasonable for the Bill to require that advance decisions to refuse treatment should be recorded in writing and witnessed by two independent persons having no financial interest in that person's estate. An exception might, however, be made where the decision was taken during ongoing medical treatment in which case it should be recorded by the doctor in charge of the treatment in the patient's notes and independently witnessed. We believe that all individuals should be encouraged to register their advance decision with their doctors. (Paragraph 205)
59. We recognise that advance decisions which they may not otherwise wish to make may be made by those suffering from depression, stress or other conditions that would affect their judgment. We also fully appreciate the potential for coercion or other malevolent actions on the part of others to secure advance decisions from vulnerable people. We therefore recommend that the Codes of Practice should require doctors to satisfy themselves that any advance refusal of treatment is valid and applicable. (Paragraph 206)
60. We also recommend that the Department should issue sensitive public guidance designed to promote better understanding of what is involved in making advance decisions. This should explicitly state that any advance decision to refuse treatment should be made voluntarily. It should also include encouragement to seek appropriate professional advice before making such decisions, aimed at ensuring that they were made in the full knowledge and understanding of any relevant medical factors and written in an appropriate form. The Departmental guidance might include a suitable specimen pro-forma. It should also encourage them to update such decisions regularly, especially in the light of relevant medical developments. (Paragraph 207)
61. We also recommend that the Codes of Practice should set out what should be considered by any doctor, when treating a person who is incapacitated and who is



known to have made an advance decision, in determining whether such an advance decision is valid and appropriate. The Code should also state that, under these circumstances, any reasons why such an advance decision was considered valid, invalid or inappropriate must be recorded in that person's health records. (Paragraph 208)

62. We believe that clause 24(4) in the draft Bill is sufficient to address the specific concern about new and unanticipated treatments becoming available which might have a bearing on an advanced decision. We recommend that specific guidance on this be given in the Codes of Practice. (Paragraph 209)
63. We believe that people, whether incapable or not, have the right to expect that they will be cared for to the highest standards. We recommend that the Codes of Practice should explicitly state that the duties and responsibilities placed on health professionals must apply equally to capable and incapacitated people. No assumption should be made that life has less value for the latter. (Paragraph 210)
64. We recommend that the Bill should seek to draw a distinction between basic care (which would include the giving of nutrition and hydration by normal means as well as actions to assist general hygiene and comfort), and the use of artificial means of nutrition and hydration, such as drips or naso-gastric tubes. We support the view that the former falls outside what is normally considered to be treatment and should always be available to people whereas the latter should be regarded as treatment in that the decision to use such artificial means is a clinical one to be made in accordance with best professional practice, and in the best interests of the patient concerned, and having consulted those specified in Clause 4 (2)(d). (Paragraph 211)
65. We further recommend that the use of such artificial means should be determined by the doctors concerned in consultation where possible with the patient's family, friends or recognised representatives, on the basis of that patient's best interests and having due regard to previously expressed wishes given in any advance decision. If a valid and clearly expressed wish not to have artificial means of nutrition and hydration is expressed, and the advance decision is otherwise valid, then that wish should be respected. (Paragraph 212)
66. We recommend that priority should be given to introducing the Mental Incapacity Bill so that account can be taken of these provisions in framing new mental health legislation. (Paragraph 217)
67. We recommend that the drafting of Clause 27 be amended to clarify its intended purpose. (Paragraph 219)
68. We recommend that the Codes of Practice include clear guidance to govern the choice of legal powers to provide treatment for mental disorder of people lacking capacity to consent. (Paragraph 222)
69. We request clarification as to whether it is intended to incorporate additional safeguards for compliant incapacitated patients into the draft MI Bill if there is likely to be a delay in implementing the provisions proposed in Part 5 of the draft Mental Health Bill. (Paragraph 225)

70. We recommend that the provisions for obtaining a second opinion currently available to patients detained under the Mental Health Act should be extended to compliant incapacitated patients requiring specified forms of treatment for mental disorder or for physical conditions, whether in hospital or in the community. The Bill should include a regulation making power to specify the types of treatment requiring a second opinion, which can be amended as new treatments are developed. (Paragraph 227)
71. Although we re-iterate our anxiety to keep up the momentum and ensure that introduction of the Bill is not unduly delayed, we recommend that the Bill should not be introduced to Parliament until it can be considered alongside comprehensive draft Codes of Practice. (Paragraph 229)
72. We agree that only those acting in a professional capacity or for remuneration should be under a duty to abide by the Codes of Practice. However, we believe that family members and carers should be strongly encouraged to follow the Codes of Practice. (Paragraph 232)
73. Given the diverse range of situations which will be covered by the statutory framework for decision-making imposed by the Bill, we consider that the processes and requirements relating to assessment of capacity would be most appropriately dealt with in a Codes of Practice, as required under Clause 30(1)(a). (Paragraph 245)
74. The Codes of Practice will need to cover, amongst other matters, the concept of best interests itself; the processes and issues involved in considering the factors set out in the Checklist in Clause 4 (including ethical issues such as confidentiality); suggestions of the types of additional factors which may be relevant in different situations and guidance on weighing up competing or conflicting concerns. (Paragraph 247)
75. The Codes of Practice will need to include, amongst other matters, a clear explanation of the general authority as the means whereby practical and legally relevant decisions can be made, in a manner that is enabling and respectful of the person lacking capacity; guidance and examples setting out when it might be "reasonable" to act; the scope of the authority and how it links with other decision-making powers; and the requirement for all decision-makers to be fully accountable for their actions. (Paragraph 249)
76. We recommend that specific requirements of a standard of conduct be included in the Codes of Practice aimed at those exercising formal powers under the Bill. (Paragraph 252)
77. We recommend that the Codes of Practice should provide details of the OPG's supervisory role and the sanctions which may apply in the event of non-compliance with the codes. (Paragraph 253)
78. we recommend that the Court's powers should include the power to remove a donee or deputy who is acting incompetently or failing to comply with the guidance given in the Codes of Practice as to the expected standard of conduct. It should be made clear to decision-makers that if their behaviour falls below the standard of conduct

set out in the Codes of Practice, the court has power to remove them as attorneys or deputies and if their conduct is criminal, they will face the prospect and consequences of prosecution. (Paragraph 254)

79. We strongly recommend that the statutory authorities should be given additional powers of investigation and intervention in cases of alleged physical, sexual or financial abuse of people lacking the capacity to protect themselves from the risk of abuse. (Paragraph 266)
80. We recommend that Clause 31 be extended to include the misappropriation of the person's property and financial assets. (Paragraph 272)
81. We understand that properly-constituted medical research is the process whereby knowledge about a specific disorder or problem is obtained in order to inform the development of new treatments or support strategies that can then be demonstrated to be effective or not through the use of controlled trials. Such information is essential if new treatments are to be developed and if the National Institute of Clinical Excellence (NICE) is to advise whether those treatments should be freely available. If properly-regulated research involving people who may lack capacity is not possible then treatments for incapacitating disorders will not be developed. (Paragraph 276)
82. We are aware of the stringent arrangements necessary before any medical research, particularly that involving human participation, can take place. Most importantly, there is a requirement that all research must be submitted to an ethics committee for their approval. These ethics committees always include lay representation and specifically address significant ethical questions such as that of informed consent. (Paragraph 277)
83. We are aware that research sanctioned by the ethics committees will vary in its invasiveness. It may extend from no more than asking questions of informants to the direct physical or psychological assessment of people with incapacity. It can also include specific investigations such as blood tests or brain scans. Such research interventions will carry with them different levels of potential inconvenience or discomfort. Informants are very likely to have the capacity to decide whether or not to participate. Assessments and many investigations of people with incapacity can only take place with their co-operation. (Paragraph 280)
84. It follows that the inclusion of statutory provisions governing such research would enable the ethical requirements that must underpin research involving people with incapacity to be clearly enshrined in statute. (Paragraph 284)
85. We conclude that a clause should be included in the Bill to enable strictly-controlled medical research to explore the causes and consequences of mental incapacity and to develop effective treatment for such conditions. This clause must include rigorous protocols to protect incapacitated adults from being exploited or harmed. (Paragraph 288)



86. We therefore recommend that the Bill should set out the key principles governing research, such as those enshrined by the World Medical Association. Those key principles should include the following:
- research involving people who may be incapacitated must be reviewed by a properly established and independent ethics committee and can only proceed if ethical permission is granted.
  - where a person has the capacity to consent then his decision whether or not to partake in research must be respected.
  - considerable care should be taken to ensure that under these circumstances consent to participate was freely given and not a consequence of coercion.
  - the inclusion of people in research, who lacked the capacity to consent, must only occur when such research has the potential for direct benefit to those with that particular problem and could not have been done through the involvement of those with capacity.
  - those undertaking research involving people lacking the capacity to consent must respect any indications that a person did not wish to participate (i.e. was dissenting).
  - any discomfort or risk involved in the research must be, at the most, minimal. (Paragraph 289)
87. We further recommend that the Codes of Practice should set out the specific issues that ethics committees should be obliged to consider when any research includes people who may be incapacitated. These should include:
- Whether the involvement of people who may be incapacitated is justified given the above.
  - Whether issues of consent and consultation with others has been properly been considered given the nature of the research.
  - Any other matters that seem relevant. (Paragraph 290)
88. We also recommend that the Codes of Practice should define the duties of research ethics committees in relation to incapacitated adults. The Codes of Practice should state that these committees must include people from outside the medical profession. (Paragraph 291)
89. We are convinced that independent advocacy services play a essential role in assisting people with capacity problems to make and communicate decisions; helping them to enforce their rights and guard against unwarranted intrusion into their lives; providing a focus on the views and wishes of an incapacitated person in the determination of their best interests; providing additional safeguards against abuse and exploitation; and assisting in the resolution of disputes. (Paragraph 296)
90. We agree that it would be inappropriate for us to recommend that resources be committed to provide a statutory right to advocacy for all people affected by the Bill's provisions. However, we recommend that a provision be included in the Bill, similar

to that in the Health and Social Care Act 2001, to empower the relevant Ministers to arrange, to such an extent as is considered necessary to meet all reasonable requirements, for the provision of independent advocacy services to incapacitated adults affected by the Bill's provisions. (Paragraph 302)

91. We recommend that the Government consider setting up an agency, similar to the Advocacy Safeguards Agency in Scotland, with the aim of promoting standards for good quality independent advocacy. (Paragraph 303)
92. We recommend that the Codes of Practice produced under the Bill provide guidance on the appropriate use of advocacy services, in particular suggesting priority situations when it may be essential for an incapacitated person to have access to an advocate. (Paragraph 306)
93. We recommend that all organisations commissioning or providing advocacy services to incapacitated adults should have satisfactory procedures in place to ensure that the standards and quality of independent advocacy services are monitored and maintained. (Paragraph 308)
94. The Department have not produced reliable estimates of the cost of the Bill or adequately consulted on likely costs. They have provisionally estimated a cost equivalent to a present value of £171m over ten years and some witnesses have identified still further costs. However, we recognise that not all the costs predicted by witnesses will necessarily add to the overall burden on taxpayers at national or local level; there may also very well be offsetting savings. (Paragraph 339)
95. Given that the Bill has been under consideration for so many years, we fail to understand why the Department were not able to produce more accurate figures and do not appear to have carried out adequate consultations on likely cost. We regret that the draft Bill was presented for Parliamentary Scrutiny without the accompanying assessments of the resource implications. We were also surprised and disappointed that the Treasury should have waived the requirement for a full resource impact assessment of costs and benefits to accompany the draft Bill. As a result of these factors, we have been placed in the invidious position of having to carry out our duty of scrutiny without any detailed indications of what the Bill might cost or what the quantum of benefits it will lead to might be. (Paragraph 340)
96. In the absence of such indications, we regret that we are unable to reach any conclusions on the resource impact of the Bill. Many of the benefits of social legislation are unquantifiable. Nevertheless, the Department's failure to provide proper estimates of costs and likely benefits has impaired the process of pre-legislative scrutiny and made it impossible for us to judge whether the benefits of the Bill may outweigh its costs or whether the likely cost might benefit people without capacity more effectively in other ways. Nor is it clear to us whether adequate trained personnel will be readily available to ensure that the Bill is implemented effectively. We can only urge that these aspects are exposed to the most rigorous scrutiny when the Bill itself comes before both Houses. (Paragraph 341)

97. We regret that the Department do not appear to have adequately addressed the important, though admittedly complex, issues involving access to information to those acting on behalf of people lacking capacity. We welcome the Department's assurance that work is in hand to resolve these issues and that consequential amendments will be included in the Bill when it is introduced. We hope that the implications can be thoroughly investigated and adequately tackled in the consequential amendments and in the Codes of Practice. But we also hope that this will not unduly delay presentation of the Bill. (Paragraph 356)
98. We were rather surprised that the Department had not included in the draft Bill any consideration of the jurisdictional implications of the different Scottish legislation for those domiciled in one jurisdiction who suffer incapacity and require decisions to be made while in the other. We acknowledge that legal complexities might be involved in some cases and welcome the Department's confirmation that they intend to provide adequately for this aspect in the Bill when it is introduced. (Paragraph 361)
99. we recommend that consideration be given to changing the Bill's title to the "Mental Capacity Bill" (Paragraph 365)



## Annex: Press Notice issued on 17 July 2003

The two Houses of Parliament have established a Joint Committee on the Draft Mental Incapacity Bill, which was published by the Government on 27 June 2003 (Cm 5859). The text of the draft Bill can be found at:

[http://www.parliament.uk/parliamentary\\_committees/jcmib.cfm](http://www.parliament.uk/parliamentary_committees/jcmib.cfm)

The remit of the Committee is to consider the draft bill, and to report on it to both Houses by the end of November 2003. The Committee will proceed in the normal manner of Select Committees, by holding hearings and receiving written evidence. The Committee will publish a report making recommendations.

### Membership

The members of the Committee are as follows:

Lord Carter (Labour) Chairman

Baroness Barker (Liberal Democrat)

Baroness Fookes (Conservative)

Baroness Knight of Collingtree (Conservative)

Baroness McIntosh of Hudnall (Labour)

Lord Pearson of Rannoch (Conservative)

Lord Rix (Crossbencher)

Baroness Wilkins (Labour)

Mr John Bercow MP (Conservative, Buckingham)

Mrs Angela Browning MP (Conservative, Tiverton and Honiton)

Mr Paul Burstow MP (Liberal Democrat, Sutton and Cheam)

Jim Dowd MP (Labour, Lewisham West)

Stephen Hesford MP (Labour, Wirral West)

Mrs Joan Humble MP (Labour, Blackpool North and Fleetwood)

Huw Irranca-Davies MP (Labour, Ogmore)

Laura Moffatt MP (Labour, Crawley)

At its first meeting on Tuesday 15 July, the Committee elected Lord Carter as Chairman. The Committee expects to start taking oral evidence in September. The programme of such evidence sessions will be announced nearer the time.

### CALL FOR EVIDENCE

The Joint Committee invites interested organisations and individuals to submit written evidence as part of its inquiry into the Draft Mental Incapacity Bill. Submissions, reflecting the guidance on written evidence given in this press notice, should reach the Committee as soon as possible and **must be submitted at the latest by Monday 1 September**.

## Scope of the Committee's inquiry

The Joint Committee expects to concentrate its Inquiry on the following themes in relation to the structure and content of the draft Bill:

- Was the consultation process preceding the publication of the draft Bill adequate and effective?
- Are the objectives of the draft Bill clear and appropriate?
- Does the draft Bill meet those objectives adequately?
- Are the proposals in the draft Bill workable and sufficient?
- Might lessons be learned from similar legislation already implemented in Scotland or elsewhere?
- Are there relevant issues not covered by the draft Bill which it should have addressed?
- In what other ways might the draft Bill be improved?

### Written evidence

All written evidence should be submitted to the Joint Committee no later than Monday 1 September. Given the limited time available for the submission of evidence and for the completion of the Committee's work, written evidence should be short and should concentrate on the major issues arising from the draft Bill.

If appropriate, written evidence should contain a brief introductory paragraph setting out, any experience of the persons or organisations submitting it relevant to the Bill.

Submissions should take the form of a memorandum and should have numbered paragraphs. An indicative length would be 1,000- 1,200 words. Memoranda which exceed five pages should be accompanied by a one-page summary. Submissions may be accompanied by background material (perhaps already published elsewhere) which would not be reprinted by the Joint Committee.

We wish to receive written evidence, if possible in MS Word or rich text format, by e-mail to [scrutiny@parliament.uk](mailto:scrutiny@parliament.uk). A single hard copy (single-sided, unbound) should also be sent to Francene Graham, Scrutiny Unit, Room G10, House of Commons, London SW1P 3JA. Fax 020 7219 8381.

Once written evidence has been submitted it becomes the property of the Committee. Those who have submitted written evidence to the Joint Committee are welcome to publish their evidence themselves (for example, by placing it on their own website). But it must not be published until after the Joint Committee has acknowledged receipt of the evidence. It must also be made clear that the document was prepared as evidence to the Joint Committee. Written submissions from those giving oral evidence will be available at the relevant hearing. Written evidence from others will either be published by the Committee with its final Report or placed in the public domain when that Report is published. Individuals and organisations considering submitting information to the

Committee that they would wish the Committee to treat as confidential should consult the Clerks in advance, initially by sending an e-mail to the address given above.

Further notices will be issued shortly, indicating how the Committee will proceed.

Ask to be added to the mailing list for future notices.

Contact: Francene Graham Committee Assistant to the Joint Committee on the Draft Mental Incapacity Bill Room G10 7 Millbank House of Commons London SW1A 0PW

Or email: [scrutiny@parliament.uk](mailto:scrutiny@parliament.uk)

Tel: 020 7219 8387

Fax: 020 7219 8381



## Formal minutes

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*Extract from House of Lords Minute of 12 June 2003*

Mental Incapacity—It was moved by the Lord Privy Seal (Lord Williams of Mostyn) that it is expedient that a Joint Committee of Lords and Commons be appointed to consider and report on any draft Mental Incapacity Bill presented to both Houses by a Minister of the Crown, and that the Committee should report on the draft Bill by the end of October 2003; the motion was agreed to and a message was ordered to be sent to the Commons to acquaint them therewith.

*Extract from Votes and proceedings of the House of Commons 10 July 2003*

Draft Mental Incapacity Bill (Joint Committee), -*Ordered*, That the Lords Message of 13th June relating to a Joint Committee of both Houses to consider and report on any draft Mental Incapacity Bill presented to both Houses by a Minister of the Crown be now considered.

That this House concurs with the Lords that it is expedient that a Joint Committee of Lords and Commons be appointed to consider and report on any draft Mental Incapacity Bill presented to both Houses by a Minister of the Crown, and proposes that the Committee should report on the draft Bill by the end of November 2003.

That a Select Committee of eight honourable Members be appointed to join with the Committee appointed by the Lords to consider any draft Mental Incapacity Bill.

That the Committee shall have power-

- (i) to send for persons, papers and records;
- (ii) to sit notwithstanding any adjournment of the House;
- (iii) to report from time to time;
- (iv) to appoint specialist advisers;
- (v) to adjourn from place to place within the United Kingdom; and

That Mr John Bercow, Mrs Angela Browning, Mr Paul Burstow, Jim Dowd, Stephen Hesford, Mrs Joan Humble, Huw Irranca-Davies and Laura Moffatt be members of the Committee-(*Charlotte Atkins.*)

Message to the Lords to acquaint them therewith.

*Extract from House of Lords Minute of 11 July 2003*

Mental Incapacity—It was moved by the Chairman of Committees that the Commons message of yesterday be now considered, and that a Committee of eight Lords be appointed to join with the Committee appointed by the Commons, to consider and

report on any draft Mental Incapacity Bill presented to both Houses by a Minister of the Crown;

That, as proposed by the Committee of Selection, the Lords following be named of the Committee:

B. Barker	B. McIntosh of Hudnall
L. Carter.	L. Pearson of Rannoch
B. Fookes	L. Rix
B. Knight of Collingtre	B. Wilkins;

That the Committee have power to agree with the Commons in the appointment of a Chairman;

That the Committee have leave to report from time to time;

That the Committee have power to appoint specialist advisers;

That the Committee have power to adjourn from place to place within the United Kingdom;

That the reports of the Committee from time to time shall be printed, notwithstanding any adjournment of the House;

That the Committee do report on the draft Bill by the end of November 2003;

And that the Committee do meet with the Committee appointed by the Commons on Tuesday 15th July at half-past three o'clock in Committee Room 5;

the motion was agreed to; and a message was ordered to be sent to the Commons to acquaint them therewith.

*Proceedings of the Joint Committee*

**Tuesday 15 July 2003**

Members present:

Baroness Barker	Baroness Knight of Collingtree
Mrs Angela Browning	Baroness McIntosh of Hudnall
Lord Carter	Laura Moffat
Jim Dowd	Lord Rix
Stephen Hesford	

Members disclosed their interests relating to the draft Bill, pursuant to the resolutions of the House of Commons 13th July 1992 and the House of Lords 2nd July 2001:

Baroness Barker declared an interest as a full time employee of Age Concern England; occasional joint work (unpaid) with Alzheimer's Disease Society and other voluntary organisations.

Lord Rix declared an interest as President of Royal Mencap Society; President of the Friends of Normansfield; Chairman of Libertas (heritage tours for people with a learning disability coupled with sensory and/or physical disabilities); Chairman of Mencap City Foundation (financial grants for projects concerned with learning disability). All the foregoing offices are honorary with no remuneration.

Lord Carter declared an interest as trusteeships with Carousel (access to the arts for learning-disabled people); Dame Vera Lynn Trust for Children with cerebral palsy; The Shaw Trust (employment of disabled people); Plunkett Foundation; Village Retail Services Association; The Andrew Carter Trust (a small family charity set up in the memory of a son which makes grants to disabled people). He is also declared that he is named on a Protection Order as the “best friend” for a lady with Alzheimer’s disease – she has no close relatives.

Baroness Wilkins declared an interest (in writing) as Vice-Chair of HAFAD (Hammersmith and Fulham Action on Disability, and life interest in income from a house in North London.

Lord Carter was called to the Chair by acclamation.

The Joint Committee deliberated.

*Ordered*, That the public be admitted during the examination of witnesses unless the Committee otherwise orders.—(*The Chairman.*)

*Ordered*, That the uncorrected transcripts of oral evidence given, unless the Committee otherwise orders, be published on the Internet.—(*The Chairman.*)

The Joint Committee further deliberated.

[Adjourned till Tuesday 9 September at half past Three o’ clock.

## **TUESDAY 9 SEPTEMBER 2003**

Members present:

Lord Carter, in the Chair.

Baroness Barker	Huw Irranaca-Davies
Mrs Angela Browning	Baroness Knight of Collingtree
Mr John Bercow	Baroness McIntosh of Hudnall
Mr Paul Burstow	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Stephen Hesford	Lord Rix
Mrs Joan Humble	

The Joint Committee deliberated.

The following declaration of relevant interests were made:



Lord Pearson of Rannoch declared an interest as Honorary President of RESCARE (The National Society for People with a mental handicap in residential and family care, and father of a 22 year old daughter with Down Syndrome.

Mrs Angela Browning declared an interest as, special counsellor National Autistic Society; member of Wessex Autistic Society and patron of Domino Appeal; patron of Tree House School for autism in London; member resources for autism; national vice president Alzheimer's Disease Society; member of all party mental health group; member of All Party Autism group all the above are non-remunerated. Also carer for adult dependant with autism.

Mrs Joan Humble declared an interest as Chair of All Party Social Services Group and President of Blackpool Advocacy, an organisation providing advocacy services in the local community for a range of individuals.

The Joint Committee deliberated.

*Ordered*, That Professor Anthony Holland and Ms Penny Letts be appointed as Specialist Advisers to assist the Committee in its inquiry into the Draft Mental Incapacity Bill.- (*The Chairman*)

The Joint Committee further deliberated.

[Adjourned till tomorrow at half past Three o'clock.

### **WEDNESDAY 10 SEPTEMBER 2003**

Members present:

Lord Carter, in the Chair.

Baroness Barker	Huw Irranaca-Davies
Mrs Angela Browning	Baroness Knight of Collingtree
Mr John Bercow	Baroness McIntosh of Hudnall
Mr Paul Burstow	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Stephen Hesford	Lord Rix
Mrs Joan Humble	

The Joint Committee deliberated.

Stephen Hesford declared an interest as vice-chair of All Party Parliamentary Group on Autism; patron of Crossroads-Wirral Caring for Carers.

Draft Mental Incapacity Bill: Mr Adrian Ward, Convenor; Mr David McClements, Member Mental Health and Disability Committee of the Law Society of Scotland; Ms Elizabeth Craigmyle, Principal Solicitor for ENABLE and member of the Mental Health and Disability Commission, Law Society of Scotland, were examined.

Professor Tom McMillan, Chair in Clinical Neuropsychology, Glasgow University; Mr Mark Ramm, Director of Clinical Forensic Psychology, Orchard Clinic, Edinburgh; Dr Keith Bowden, Consultant Clinical Psychologist, Forth Valley Primary Care NHS Trust; Dr Donald Lyons, Consultant in Psychiatry of Old Age and Medical Adviser for Elderly Services for Greater Glasgow Primary Care NHS Trust, were examined.

[Adjourned till Tuesday 16 September at half past Three o' clock.

## **TUESDAY 16 SEPTEMBER 2003**

Members present:

Lord Carter, in the Chair.

Baroness Barker	Baroness Knight of Collingtree
Mr Paul Burstow	Baroness McIntosh of Hudnall
Jim Dowd	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Mrs Joan Humble	Lord Rix
Huw Irranaca-Davies	

The Joint Committee deliberated.

Mr Paul Burstow declared an interest as Co-Chair, All Party Parliamentary Group on Ageing and Older People; Vice Chair All Party Group on Disability and Front Bench Spokesperson, Liberal Democrats, Older People.

Draft Mental Incapacity Bill: Mr Clive Evers, Alzheimer's Society, Mr Simon Foster, Mind, Mr Roger Goss, Patient Concern, Dr Andrew McCulloch, Mental Health Foundation, Ms Pauline Thompson, Age Concern and Ms Kathryn Willmington, Help the Aged, were examined.

[Adjourned till tomorrow at half past Three o'clock.

## **WEDNESDAY 17 SEPTEMBER 2003**

Members present:

Lord Carter, in the Chair

Baroness Barker	Baroness Knight of Collingtree
Mr John Bercow	Baroness McIntosh of Hudnall
Mr Paul Burstow	Laura Moffat
Jim Dowd	Lord Pearson of Rannoch
Baroness Fookes of Plymouth	Lord Rix
Stephen Hesford	

The Joint Committee deliberated.

Draft Mental Incapacity Bill: Mr Steve Broach, National Autistic Society, Ms Caroline Clipson, Scope, Mr Richard Kramer, Turning Point and Ms Hazel Morgan, Foundation for People with Learning Disabilities, were examined.

[Adjourned till Wednesday 8 October at half past Three o'clock.

### **WEDNESDAY 8 OCTOBER 2003**

Members present:

Lord Carter, in the Chair

Mrs Angela Browning	Baroness Knight of Collingtree
Mr Paul Burstow	Baroness McIntosh of Hudnall
Jim Dowd	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Stephen Hesford	Lord Rix
Mrs Joan Humble	

The Joint Committee deliberated.

Draft Mental Incapacity Bill: Dr Michael Wilks and Dr Vivienne Nathanson, British Medical Association, Medical Ethics Committee, were examined.

Dr Karen Elhert, Dr Camilla Herbert, Professor Glynis Murphy, Dr Peter Kinderman and Dr Catherine Dooley, British Psychological Society and Dr Tony Zigmond, Royal College of Psychiatrists, were examined.

[Adjourned till tomorrow at half past Three o'clock.

### **THURSDAY 9 OCTOBER 2003**

Members present:

Lord Carter, in the Chair.

Mrs Angela Browning	Huw Irranaca-Davies
Mr Paul Burstow	Baroness Knight of Collingtree
Jim Dowd	Baroness McIntosh of Hudnall
Baroness Fookes of Plymouth	Lord Rix
Mrs Joan Humble	

The Joint Committee deliberated.



The Draft Mental Incapacity Bill: Professor the Baroness Finlay of Llandaff, was examined.

Archbishop Peter Smith, Catholic Bishops' Conference of England and Wales and Dr Helen Watt of the Linacre Centre for Healthcare Ethics; Dr Philip Howard and Dr Adrian Treloar, Guild of Catholic Doctors, Mr James Bogle, Catholic Union; Dr Gregory Gardener and Dr Gillian Craig, Medical Ethics Alliance; The Right Reverend and Right Honourable the Lord Habgood and Lay Canon Claire Foster, Church of England Archbishops' Council, were examined.

[Adjourned till Tuesday 14 October at half past Three o'clock.

## **TUESDAY 14 OCTOBER 2003**

Members present:

Lord Carter, in the Chair

Baroness Barker	Huw Irranaca-Davies
Mrs Angela Browning	Baroness Knight of Collingtree
Mr Paul Burstow	Baroness McIntosh of Hudnall
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Stephen Hesford	Lord Rix
Mrs Joan Humble	Baroness Wilkins

The Joint Committee deliberated.

Draft Mental Incapacity Bill: Mr John Dixon and Mr Graham Collingridge, Association of Directors of Social Services, were examined.

Master Denzil Lush, Court of Protection, was examined.

Professor John Williams, University of Wales (Aberystwyth), was examined.

[Adjourned till tomorrow at half past Three o'clock.

## **WEDNESDAY 15 OCTOBER 2003**

Members present:

Lord Carter, in the Chair.

Baroness Barker	Huw Irranaca-Davies
Mr John Bercow	Baroness Knight of Collingtree
Mrs Angela Browning	Baroness McIntosh of Hudnall
Jim Dowd	Laura Moffat
Baroness Fookes of Plymouth	Lord Rix
Stephen Hesford	Baroness Wilkins
Mrs Joan Humble	

The Joint Committee deliberated.

Draft Mental Incapacity Bill: Ms Vicki Chapman, Mr Niall Baker, Mr Luke Clements and Mr Peter Raymond for the Law Society of England and Wales, were examined.

[Adjourned till Tuesday 21 October at half past Three o'clock.

**TUESDAY 21 OCTOBER 2003**

Members present:

Lord Carter, in the Chair

Baroness Barker	Baroness Knight of Collingtree
Mr John Bercow	Baroness McIntosh of Hudnall
Mrs Angela Browning	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Stephen Hesford	Lord Rix
Mrs Joan Humble	Baroness Wilkins
Huw Irranaca-Davies	

The Joint Committee deliberated.

Draft Mental Incapacity Bill: Ms Simone Aspis and Mr Richard Downs, Changing Perspectives; Mr Andrew Lee and Mr Nico Mac Given, People First; Dr Jean Collins and Mr Mark Brookes, Values into Action, were examined.

Draft Mental Incapacity Bill: Dr Maurice Brook, Mrs Mary Pearson and Mr David Sugden, RESCARE; Mr James Allen, Care UK and Mr Simon Cramp, New Dimensions Group and MENCAP, were examined.

[Adjourned till tomorrow at half past Three o'clock.

**WEDNESDAY 22 OCTOBER 2003**

Members present:

Lord Carter, in the Chair

Baroness Barker	Baroness Knight of Collingtree
Mr John Bercow	Baroness McIntosh of Hudnall
Mrs Angela Browning	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Mrs Joan Humble	Lord Rix
Huw Irranaca-Davies	Baroness Wilkins

The Joint Committee deliberated.

Draft Mental Incapacity Bill: The Lord Filkin CBE, Parliamentary Under-Secretary of State and Ms Claire Johnston, Head of Legal Advice and Legislation Division, Department for Constitutional Affairs; Ms Rosie Winterton MP, Minister of State and Mr Adrian Sieff, Head of Mental Health Legislation, Department of Health, were examined.

[Adjourned till Tuesday 11 November at Three o'clock.

## **TUESDAY 11 NOVEMBER 2003**

Members present:

Lord Carter, in the Chair

Baroness Barker	Mrs Joan Humble
Mrs Angela Browning	Baroness Knight of Collingtree
Mr Paul Burstow	Baroness McIntosh of Hudnall
Jim Dowd	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Stephen Hesford	Baroness Wilkins

The Joint Committee deliberated.

[Adjourned till tomorrow at Three o'clock.

## **WEDNESDAY 12 NOVEMBER 2003**

Members present:

Lord Carter, in the Chair

Baroness Barker	Baroness Knight of Collingtree
Mr Paul Burstow	Baroness McIntosh of Hudnall
Jim Dowd	Laura Moffat
Baroness Fookes of Plymouth	Lord Pearson of Rannoch
Stephen Hesford	Lord Rix
Mrs Joan Humble	Baroness Wilkins
Huw Irranaca-Davies	

The Joint Committee deliberated.

[Adjourned till Monday 17 November at Three o'clock



## MONDAY 17 NOVEMBER 2003

Members present:

Lord Carter, in the Chair.

Baroness Barker	Huw Irranaca-Davies
Mr Paul Burstow	Baroness Knight of Collingtree
Jim Dowd	Baroness McIntosh of Hudnall
Baroness Fookes of Plymouth	Laura Moffat
Stephen Hesford	Baroness Wilkins

The Joint Committee considered the draft report.

Paragraphs 1 to 288 were agreed to.

Paragraph 289 read as follows:

**We therefore recommend that the Bill should set out the key principles governing research, such as those enshrined by the World Medical Association. Those key principles should include the following:**

- **research involving people who may be incapacitated must be reviewed by a properly established and independent ethics committee and can only proceed if ethical permission is granted.**
- **where a person has the capacity to consent then his decision whether or not to partake in research must be respected.**
- **considerable care should be taken to ensure that under these circumstances consent to participate was freely given and not a consequence of coercion.**
- **the inclusion of people in research, who lacked the capacity to consent, must only occur when such research has the potential for direct benefit to those with that particular problem and could not have been done through the involvement of those with capacity.**
- **those undertaking research involving people lacking the capacity to consent must respect any indications that a person did not wish to participate (i.e. was dissenting).**
- **any discomfort or risk involved in the research must be, at the most, minimal.**

An amendment proposed, in line 3, after the word “following” to add the words “People judged to be incapable and unable to make decisions for themselves should not be used in medical research experimentation” – *The Baroness Knight of Collingtree*.

Question put, That the Amendment be made.

*Ayes*

Baroness Knight of Collingtree

*Noes*

Lord Carter

Baroness Barker

Paul Burstow

Jim Dowd

Baroness Fookes of Plymouth

Mr Stephen Hesford

Huw Irranca-Davies

Baroness McIntosh of Hudnall

Baroness Wilkins

Paragraph agreed to.

Paragraphs 290 to 365 were agreed to.

*Resolved*, That the Joint Committee agreed that the draft report, as amended, be the report of the Joint Committee to both Houses.

The Annexes to the report were agreed to.

The Committee ordered the Chairman to make the report to the House of Lords and Jim Dowd to report to the House of Commons.

*Ordered*, The a guide to the Report in easy read format be published separately.

# Witnesses

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## Wednesday 10 September 2003

**Mr Adrian Ward**, Convenor, and **Mr David McClements**, Member, Mental Health and Disability Committee, Law Society of Scotland; **Ms Elizabeth Craigmyle**, Principal Solicitor, ENABLE, Law Society of Scotland

Ev 3

**Professor Tom McMillan**, Chair in Clinical Neuropsychology, Glasgow University, **Mr Mark Ramm**, Director of Clinical Forensic Psychology, Orchard Clinic, Edinburgh, **Dr Keith Bowden**, Consultant Clinical Psychologist, Forth Valley Primary Care NHS Trust, and **Dr Donald Lyons**, Consultant in Psychiatry of Old Age and Medical Adviser for Elderly Services for Greater Glasgow Primary Care NHS Trust.

Ev 22

## Tuesday 16 September 2003

**Mr Clive Evers**, Alzheimer's Society, **Mr Simon Foster**, Mind, **Mr Roger Goss**, Patient Concern, **Dr Andrew McCulloch**, Mental Health Foundation, **Ms Pauline Thompson**, Age Concern, and **Ms Kathryn Willmington**, Help the Aged, Making Decisions Alliance.

Ev 54

## Wednesday 17 September 2003

**Mr Steve Broach**, National Autistic Society, **Ms Caroline Clipson**, SCOPE, **Mr Richard Kramer**, Turning Point, **Ms Hazel Morgan**, Foundation for People with Learning Disabilities, and **Ms Susannah Seyman**, Down's Syndrome Association, Making Decisions Alliance.

Ev 69

## Wednesday 8 October 2003

**Dr Michael Wilks**, Chairman, Medical Ethics Committee and **Dr Vivienne Nathanson**, Director of Professional Affairs, British Medical Association.

Ev 90

**Professor Glynis Murphy**, Professor of Clinical Psychology in Learning Disabilities, **Dr Karen Ehlert**, Honary Secretary of the Division of Clinical Psychology, **Dr Peter Kinderman**, Reader of Clinical Psychology at the University of Liverpool, **Dr Catherine Dooley**, Consultant in Clinical Psychology, **Dr Camilla Herbert**, Clinical Psychologist specialising in neuro rehabilitation, British Psychological Society, and **Dr Tony Zigmund**, Consultant in General Adult Psychiatry, Royal College of Psychiatrists.

Ev 109

## Thursday 9 October 2003

**Professor The Baroness Finlay of Llandaff.**

Ev 125

**Archbishop Peter Smith**, Catholic Bishops' Conference of England and Wales, **Dr Helen Watt**, Linacre Centre for Healthcare Ethics, **Dr Philip Howard** and **Dr Adrian Treloar**, Guild of Catholic Doctors, **Dr Gregory Gardener**, **Dr Gillian Craig** and **Dr Jafer Quereschi**, Medical Ethics Alliance, **Lord Habgood** and **Mrs Claire Foster**, Church of England Archbishops' Council, and **Mr James Bogle**, Lawyer, Catholic Union.

Ev 150



## Tuesday 14 October 2003

<b>Mr John Dixon</b> , Chairman, National Disability Committee, <b>Mr Graham Collingridge</b> , Member, Mental Health Strategy Group, Association of Directors of Social Services. <b>Professor John Williams</b> , University of Wales (Aberystwyth)	Ev 173
<b>Mr Denzil Lush</b> , Master of the Court of Protection	Ev 186
<b>Professor John Williams</b> , University of Wales (Aberystwyth)	Ev 199

## Wednesday 15 October 2003

<b>Ms Vicki Chapman</b> , Head of Law Reform, <b>Mr Peter Raymond</b> , Practising Solicitor, <b>Mr Niall Baker</b> , Practising Solicitor, and <b>Mr Luke Clements</b> , Practising Solicitor, The Law Society.	Ev 208
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## Tuesday 21 October 2003

<b>Ms Simone Aspis</b> and <b>Mr Richard Downs</b> , Changing Perspectives. <b>Mr Andrew Lee</b> and <b>Mr Nico MacGiven</b> , People First. <b>Dr Jean Collins</b> and <b>Mr Mark Brookes</b> , Values into Action. <b>Dr Maurice Brook</b> , <b>Mrs Mary Pearson</b> and <b>Mr David Sugden</b> , RESCARE; <b>Mr James Allen</b> , Care UK, and <b>Mr Simon Cramp</b> , New Dimensions Group and MENCAP.	Ev 248
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## Wednesday 22 October 2003

<b>The Lord Filkin</b> , CBE, Parliamentary Under-Secretary of State, <b>Ms Claire Johnston</b> , Head of Legal Advice and Legislation Division, Department for Constitutional Affairs, <b>Ms Rosie Winterton MP</b> , Minister of State, and <b>Mr Adrian Sieff</b> , Head of Mental Health Legislation, Department of Health.	Ev 268
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Additional papers have been received from the following and have been reported to both Houses but to save printing costs they have not been printed and copies have been placed in the House of Commons Library where they may be inspected by members. Other copies are in the Record Office, House of Lords and are available to the public for inspection. Requests for inspection should be addressed to the Record Office, House of Lords, London SW1. (Tel 020 7219 3074) hours of inspection are from 9:30am to 5:00pm on Mondays to Fridays.

Mr P Alfred (MIB001)  
 Mr I Thompson (MIB 002)  
 Mrs M Deverson (MIB 003)  
 Mrs M Farmer (MIB 004)  
 Miss M Lefebure (MIB 005)  
 B Kidd (MIB 006)  
 Dr J Harvey (MIB 007)  
 Miss R Sciendorfer (MIB 008)  
 Mr G Scott (MIB 010)  
 Mr C Redding (MIB 011)  
 Mrs M Clark (MIB 012)  
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 Mrs W Walker (MIB 014)  
 Mrs C Russell (MIB 015)  
 Ms R Ryan (MIB 016)  
 Ms A Ryder (MIB 017)  
 Mr I Scott (MIB 018)  
 Rev M Garvey, Church of the Blessed Sacrament (MIB 019)  
 Mr B Walker (MIB 022)  
 C Draper (MIB 023)  
 Mr B Rooney (MIB 026)  
 Mr L Noble (MIB 027)  
 H Gallagher (MIB 028)  
 Mr K Prendergast (MIB 029)  
 Mrs M Ollerenshaw (MIB 030)  
 Mr B Gregory (MIB 031)  
 Mr S Belderbos (MIB 032)  
 Mr R Hallaway (MIB 033)  
 Mrs S Yates (MIB 034)  
 Mrs T Hill (MIB 035)  
 Mrs S Butcher (MIB 036)  
 Mrs B Solez (MIB 037)  
 Ms J Belderbos (MIB 038)  
 Mr C O'Brien (MIB 039)  
 Mr & Mrs D Philpott (MIB 040)

Mrs P Turner (MIB 041)  
Mrs F Crocker (MIB 044)  
Miss C Shaw (MIB 045)  
Ms C Warnett (MIB 046)  
Mr R Isaacs (MIB 047)  
Mr & Mrs J Golden (MIB 048)  
Miss E O'Neill (MIB 049)  
Mr G McMahon (MIB 051)  
Mr D McNair (MIB 052)  
Mr D Jones (MIB 053)  
Mr S Goldspink (MIB 054)  
Mr M Tierney (MIB 055)  
Mr F J G Carville (MIB 056)  
Mr J S Wood (MIB 057)  
Mr and Mrs J D Williamson (MIB 059)  
Mr C Mason (MIB 060)  
Mr C Cheeseman (MIB 064)  
Service User Committee of Freeway/ ECHO User Group (MIB 065)  
Mr B J Barrell (MIB 069)  
Mr A Challoner (MIB 070)  
Mrs B Whitaker (MIB 072)  
Mr L W Colebrook (MIB 073)  
Ms M Layng (MIB 075)  
Ms H Dyer (MIB 076)  
Ms C Bromley-Martin (MIB 077)  
Mrs P G Clark (MIB 078)  
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Mr J H C Rowe (MIB 080)  
Mrs A Ford (MIB 081)  
Mrs D Johnson (MIB 082)  
Mrs S Round (MIB 083)  
Mr and Mrs G D Tyldesley, St Marys Cemetery House (MIB 084)  
Mr C Mann (MIB 085)  
Ms P Fewell (MIB 086)  
Ms A Walker (MIB 087)  
Ms E Morris, Kettering General Hospital (MIB 088)  
Mrs J Czech (MIB 089)  
Mrs M Winton (MIB 090)  
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Mr P Millar (MIB 092)  
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Rev A Cussen (MIB 095)  
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Ms A Jones (MIB 113)  
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Mr N Bellord (MIB 120)  
Mr P Howell (MIB 121)  
A Maher (MIB 122)  
Mrs E Sephton (MIB 123)  
Ms S Taylor (MIB 124)  
Mrs L Haythorne (MIB 125)  
Mr R Armstrong (MIB 126)  
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Mr M Williams (MIB 128)  
Mr J Donelon (MIB 129)  
Mr M Tuttle (MIB 131)  
Miss S Whitehead (MIB 132)  
D Bevan (MIB 134)  
Mr Torevell (MIB 135)  
Ms I Winter (MIB 136)  
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Ms A Sullivan (MIB 155)  
Mr M McGhee, St Josephs (MIB 156)  
Mrs M Reynolds (MIB 157)  
Mr & Mrs C E Lovelock (MIB 158)  
R Drake (MIB 161)  
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Mr P Ingram (MIB 170)  
Mrs M McClinton (MIB 171)  
Mr & Mrs R Simpson (MIB 172)  
Dr A Armour (MIB 174)  
Mr C Archley (MIB 175)  
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Mr & Mrs J McCormack (MIB 194)  
Mrs A Cartwright (MIB 195)  
Miss M Towey (MIB 196)  
Mr F Simmons (MIB 197)  
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Mrs M Biddulph (MIB 200)  
Ms F Smart (MIB 201)  
Mr P Smith (MIB 202)  
Father J Carter (MIB 205)

Mrs K Treble (MIB 207)  
Mr R Simpson (MIB 208)  
Ms S Cartledge (MIB 209)  
Mr I Humphrey (MIB 210)  
Mr & Mrs C Ross (MIB 211)  
Sister K Holmstrom (MIB 212)  
Mr M Turtle (MIB 213)  
Mrs M Keeley (MIB 214)  
Mrs E Conway (MIB 215)  
Mrs M Mendez (MIB 215a)  
Dr S Hughes (MIB 216)  
Mr D Hill (MIB 217)  
Ms Y Carter (MIB 218)  
Mrs S Orritt (MIB 219)  
Mr L Oates, Official Solicitor and Public Trustee (MIB 221)  
Mr C Teear (MIB 222)  
Mr J Heywood (MIB 223)  
Mrs E McHugh (MIB 224)  
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Mr & Mrs R Gainford (MIB 230)  
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M Hargreaves (MIB 251)  
Mrs E Gallacher (MIB 252)



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J Crawley (MIB 255)  
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Mrs Y Phillpox (MIB 277)  
A Tobarne (MIB 278)  
Mr & Mrs J Whittaker (MIB 279)  
S King (MIB 280)  
Mr & Mrs B King (MIB 281)  
J Hudson (MIB 282)  
Mrs M Hughes (MIB 283)  
Mr A Baker (MIB 284)  
Mr P Ellis (MIB 285)  
N J Law (MIB 286)  
Mrs M Whilcher (MIB 287)  
Rev V Melia (MIB 288)  
Mrs M J Cooper (MIB 289)  
Mrs A Farmer (MIB 290)  
Mrs K McVey (MIB 291)  
Mrs A Duffey (MIB 292)  
Miss M McClean (MIB 293)  
Mrs M Phillison (MIB 294)  
J McCallister (MIB 295)  
H Barr (MIB 296)  
Mrs J Fieldhouse (MIB 297)

Ms M Goodman (MIB 298)  
Mrs S Moore (MIB 299)  
Mr P John (MIB 301)  
Mrs J Holmes (MIB 302)  
W Barnes (MIB 303)  
Mrs J Gannon (MIB 304)  
Mr & Mrs M Lally (MIB 305)  
A Molyneux (MIB 306)  
Mrs C Clery (MIB 307)  
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Ms M Henry (MIB 310)  
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Mr & Mrs F Berridge (MIB 314)  
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Mr & Mrs C Parish (MIB 328)  
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Ms R Kennedy (MIB 331)  
Ms G Mason (MIB 332)  
Ms V Lowe (MIB 334)  
Mr J Keenan, St Puis X Church (MIB 335)  
Mr M King, Bupa Hospital (MIB 336)  
Mrs E Bernard (MIB 338)  
Mrs P Hastings (MIB 340)  
Miss J McCabe (MIB 342)  
Mrs C Anderson (MIB 343)  
Mr J Roarty (MIB 344)  
Ms C Han (MIB 345)  
Ms J Crane (MIB 346)  
Ms M Docherty (MIB 347)  
Mr & Mrs P Sonne (MIB 348)  
Mrs J Green (MIB 349)  
Mr P Allington (MIB 350)

The Blessed Sacrament (MIB 351)  
Mrs M Carr (MIB 353)  
Mrs A Humphreys (MIB 354)  
Ms J Edwards (MIB 355)  
J Baldwin (MIB 356)  
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